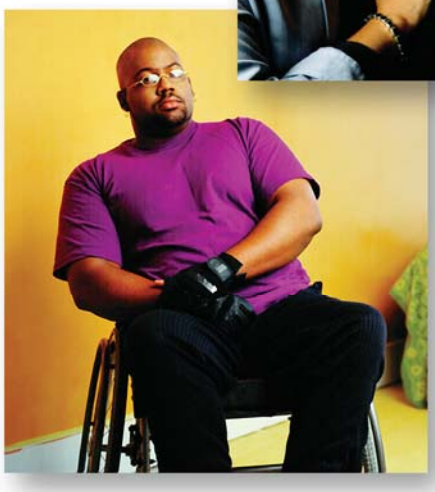
Real Choice Systems Change Grant Program

Increasing Options for Self-Directed Services

Initiatives of the FY 2003 Independence Plus Grantees



U.S. Department of Health and Human Services
Centers for Medicare & Medicaid Services

December 2007

Increasing Options for Self-Directed Services

Initiatives of the FY 2003 Independence Plus Grantees

Janet O'Keeffe, Dr.P.H., R.N.

Christine O'Keeffe, B.A.

Joshua M. Wiener, Ph.D.

Kristin Siebenaler, M.P.A.

CMS Project Officer: Cathy Cope

Centers for Medicare & Medicaid Services
7500 Security Boulevard, Mail Stop S2-14-26
Baltimore, MD 21244-1850

RTI International

CMS Contract No. 500-00-0044, TO #2

December 2007

This project was funded by the Centers for Medicare & Medicaid Services under contract no. CMS-500-00-0044, TO #2. The statements contained in this report are solely those of the authors and the Systems Change Grantees and they do not necessarily reflect the views or policies of the Centers for Medicare & Medicaid Services.

Contents

Exhibits

Executive Summary

As part of the New Freedom Initiative, in 2001 Congress provided funds for the Real Choice Systems Change Grants for Community Living program (hereafter, Systems Change grant program) in FY 2001 through FY 2006. One of the goals of the New Freedom Initiative is to empower people with disabilities to take more control of their lives.

This report is one in a series addressing major systems change topic areas in the Systems Change grant program. It describes the activities of 12 Grantees that received Independence Plus (IP) grants in fiscal year (FY) 2003 and are using them to increase self-directed services options for persons of all ages with disabilities or chronic illnesses. The report discusses a range of issues that Grantees have encountered while implementing IP initiatives.

Its primary purpose is to provide information that states and stakeholders will find useful in planning, implementing, or expanding self-direction programs, whether through solely state-funded programs or the Medicaid program.

In 2002, also as part of the New Freedom Initiative, the Centers for Medicare & Medicaid Services (CMS) began the Independence Plus Initiative to promote self-direction of services and supports by persons of all ages with disabilities and their families. In its description of the Initiative, CMS defined a self-directed services program as "a state Medicaid program that presents individuals with the option to control and direct Medicaid funds identified in an individual budget." CMS also stated that "the requirements for a comprehensive self-directed services program, or Independence Plus, include the following:

- *Person-centered planning*—A process, directed by the participant, intended to identify the strengths, capacities, preferences, needs and desired outcomes of the participant.
- *Individual budgeting*—The total dollar value of the services and supports, as specified in the plan of care, under the control and direction of the program participant.
- *Self-directed services and supports*—A system of activities that assist the participant to develop, implement and manage the support services identified in his/her individual budget.
- *Quality assurance and quality improvement*—The QA/QI model will build on the existing foundation, formally introduced under the CMS Quality Framework, of discovery, remediation and continuous improvement."

In 2003, to further encourage states to offer self-directed services options, CMS awarded $5.4 million in IP grants to Colorado, Connecticut, Florida, Georgia, Idaho, Louisiana, Maine,

Massachusetts, Michigan, Missouri, Montana, and Ohio under the Systems Change grant program.

States receiving IP grants could (1) develop new home and community-based services (HCBS) or research and demonstration (R&D) waiver programs (authorized by sections 1915(c) and 1115, respectively, of the Social Security Act) or amend existing self-direction programs to incorporate the IP features; (2) build capacity to strengthen new or existing self-direction programs in any of the IP required areas; (3) build provider capacity under the self-directed services option; and/or (4) hire personnel to research self-direction program designs or funding opportunities with the expectation of submitting an IP waiver application or amending an existing waiver to include IP features.

IP Program Design and Development

IP programs have complex operational details, and designing them to meet the needs of all stakeholders is a complicated process.

Selecting a Medicaid Authority. States first had to decide which Medicaid authority to use for their IP programs. At the time the grants were awarded, states generally used the HCBS or R&D authorities. Each option has its pros and cons, but states ultimately based their decision on their unique circumstances: whether they had an existing self-direction program under either of the authorities, their policy goals, availability of state staff, and political factors.

During the grant period, federal policy regarding self-direction in Medicaid HCBS changed, and, as a consequence, a few IP Grantees revised their initial plans concerning which Medicaid authority to use for developing and implementing an IP program. Rather than applying for a new IP waiver, some Grantees began considering amendments to existing waiver programs in order to add or expand self-direction options.

Involving Stakeholders. Grantees engaged in a wide range of outreach activities to ensure consumer and other stakeholder input in the design of their IP programs. States established and utilized formal task forces or work groups that included consumers, providers, advocates, and state staff who collaborated in designing the new self-direction option. Others conducted focus groups with waiver participants, and one state used a consumer-driven participatory action research group to help develop an IP quality management system.

Person-Centered Planning. Person-centered planning (PCP) is an assessment and service planning process directed by the participant, with assistance as needed or desired from a representative or other person chosen by the participant. PCP is the foundation for self-direction, and the IP grant initiatives included activities to promote the use of PCP, primarily

through education and training. Georgia recently implemented PCP in all of its waiver programs in both the traditional service delivery model and the self-directed services model.

Based on feedback from participants, Montana is simplifying the training, assessment, and enrollment process for its new IP waiver program. Grant staff noted, in retrospect, that its initially cumbersome and complicated planning process limited support brokers' effectiveness in working with participants and hindered program enrollment. They recommended that other states (1) try not to "person-center the process to death like we did," (2) test the planning process with a few participants and providers, and (3) simplify the procedures.

Individual Budgeting. Individual budgeting allows states to better match a program's benefits to participants' needs by allowing participants to exercise choice and control over a specified amount of funds. With budget authority, participants can, at a minimum, make decisions about the amount that will be paid for each service and support in accordance with the State's policies, and select providers and review and approve their invoices. States that used their grants to develop individual budgeting mechanisms had to grapple with both methodological challenges and stakeholder concerns.

For example, Georgia developed a uniform methodology to calculate individual budgets for waiver participants and then found that the individual budgeting formula resulted in changes (both decreases and increases) in some individuals' allocations. To ensure continuity of services for participants who are transitioning to the individual budget service option, the State is using a process in which historical costs will initially contribute more to the individual budget amount but will decrease over time.

Connecticut found that moving from capitated program-based mental retardation (MR) services to individual budgets presented a major paradigm shift, and some providers, consumers, and family members had difficulty understanding how the new system worked. To address this, the State is (1) offering information sessions for providers and including them in a work group to address rate modifications, and (2) educating consumers and their families about the new system.

Services to Support Participants in Self-Direction Programs. CMS requires self-direction programs to provide information, training, counseling, and assistance to participants to enable them to manage and direct their services and budgets. Typically, participants receive support to develop their individualized budget and spending plan, hire and manage workers, and perform fiscal and employer-related functions. Some participants may be able to handle all of these tasks with minimal or no assistance, but many want support to participate in self-direction programs, particularly with employer-related tasks.

Financial management services (FMS) play a crucial role in supporting participants to fulfill their employer-related payroll, tax filing, and reporting responsibilities. When designing and implementing FMS, states have to choose among different FMS models and determine which options will be available to participants; for example, will the participant be the employer of record, enter into a co-employer relationship with an FMS entity, or will there be a choice between these two options? States also have to make decisions about operational details, such as payment processes, as well as the specific roles and responsibilities that FMS providers will assume (e.g., conducting criminal background checks). Finally, they have to decide whether FMS will be considered a waiver service, paid for out of an individual's budget, or a Medicaid administrative expense. Georgia limited enrollment in its new self-direction option to "work out the kinks" in FMS—which it felt was particularly important when dealing with new fiscal agents. With a small number of participants, policies can be revised very quickly if needed.

About half of the Grantees worked on developing support broker models or conducted training about the role. Support brokers (also known as "independence advisors," "consultants," "counselors," or "case managers" in some programs) are chosen by participants (or a parent/guardian for minors) to serve as their personal agent in securing supports that meet their needs as identified in their support plan. Support brokers' responsibilities include helping participants create spending plans and locating employees and resources. As with FMS, in addition to choosing a specific support broker model, states must also decide whether support brokers will be a waiver service paid for out of a participant's individual budget, or as a Medicaid administrative expense.

Georgia developed a process to recruit, train, and certify support brokers to work with persons choosing to self-direct HCBS services. Ohio conducted statewide trainings for state and county staff on the support broker's role and responsibilities in preparation for implementing the service for consumers; Maine developed training curricula for support brokers that specifically address distinctions between support broker services and case management services.

Montana's grant work group believed that its traditional case management model using a nurse and social work team was inappropriate for self-directed services and wanted to use the independent living and PCP philosophy for support broker services. In response, the State expanded the provider base for support brokers to include a diverse group of entities committed to self-direction principles and the PCP philosophy: Independent Living Centers, waiver case management teams, Area Agencies on Aging, and Tribal agencies.

Quality Assurance and Quality Improvement. States developed policies and procedures to address quality assurance issues, specifically the development of policies and procedures for individualized backup plans and critical incident reporting. For example, Idaho requires

that backup plans specify three ways to get help when the primary support is absent and, if applicable, to address community-wide emergencies, such as threatening weather or electrical outages, and other circumstances that may create safety issues or support barriers. Montana developed an individual risk assessment tool to guide participants through a process of developing plans to reduce risk. Consumers and independence advisors are trained to use the tool as part of the PCP process.

Colorado had originally planned to establish a new statewide critical incident management system and a new statewide emergency backup system for all current and future self-direction programs. However, an assessment by grant staff of Colorado's current statewide systems found that they were designed for services provided by agencies or institutions and do not meet the needs of participants in self-direction programs. Because the State's self-direction programs already have mechanisms for emergency backup and critical incident management, which have demonstrated a high level of participant satisfaction, the Grantee determined that it was unnecessary to establish new statewide systems for self-direction programs. However, grant staff, consumers, and stakeholders agreed that improvements were needed to better support consumers in both preventing and dealing with critical incidents and in meeting emergency backup needs.

Implementing IP Programs: Enrollment Challenges. Grantees found that a number of factors can serve as disincentives to enrollment in a self-direction program that provides an individual budget. For example, if a state already allows consumers to hire and dismiss their workers and they are satisfied with their services, these consumers may have little or no incentive to transition to a more complex system requiring them to assume new responsibilities for directing an individual budget. Missouri grant staff found that enrollment was slow because individuals who need around-the-clock care require more than four workers to provide this care, and state regulations oblige employers with more than four employees to provide workers' compensation insurance, which would have to be paid from the individual budget. The State has not yet been able to find reasonably priced insurance, and too high a cost could result in a reduction in the amount available for services, creating a disincentive to enroll. Some families cover workers by adding riders to their homeowners insurance, but this practice might create problems if their insurance were canceled following a claim.

Conclusions

This report describes the initiatives of 12 Systems Change Grantees to develop new self-direction programs that embody the requirements of CMS's Independence Plus Initiative. The focus of these grants is on program design and development rather than implementation; thus their initiatives generally reflect issues that must be addressed at the beginning of the process.

States receiving IP grants faced several issues and decisions in designing their initiatives, among them the following:

- States had to determine which Medicaid authority to use for their IP program. Since the IP grants were awarded, federal policy has evolved to provide states with additional options to offer self-directed services, such as the new options under the Deficit Reduction Act of 2005 (Pub. L. 109-17—including the HCBS state plan option under section 1915(i) of the Social Security Act and the Self-Directed Personal Assistance Services state plan option under section 1915(j) of the Act). As a consequence, states can choose one of many options or use several options to offer self-directed services to different populations.

- As with all efforts to reform the long-term care system, Grantees recognized that successful design and implementation of a self-direction program require the involvement and buy-in of key stakeholders, including consumers, caregivers, providers, and relevant state agencies. Task forces, committees, and work groups are typical examples of mechanisms that states have used to involve stakeholders and obtain their input.

- A key component of the IP model is person-centered planning, which seeks to shift control of service planning from professionals to participants. However, some participants may not want to engage in a complex and time-consuming PCP process in order to receive services. One way to address this concern is to allow participants to lead the planning process and to determine for themselves how much information they want to provide about their life goals.

- The key feature that distinguishes IP programs from other self-direction programs is participant control over an individual budget. The range of services that participants can direct in their individual budgets varied among states. Some limited the budget to personal care services, others included any service covered by the waiver program, and still others included an array of goods and services. Developing methods for calculating individual budgets proved to be a challenge in some states, and Grantees noted the importance of education and training for both providers and consumers to ensure that everyone (1) understands how budgets will be calculated and (2) has confidence that the process is both fair and equitable and that individual budgets will be sufficient to provide needed services.

- The basic assumption of IP is that consumers, with the appropriate services and supports, are capable of making the choices that affect their lives and managing their services and supports in their service plans and budgets. To enable maximum participation in self-direction programs, Grantees worked to establish financial

management services and support broker services but employed different approaches for providing these services to address stakeholder concerns and specific challenges (e.g., a shortage of support brokers in rural areas).

In conclusion, the activities of IP Grantees are part of a range of activities supported by the Centers for Medicare & Medicaid Services to expand self-direction of long-term care services and supports. Some of the Grantees have made greater strides than others, but all have laid the groundwork for increasing the number of individuals who have the option to direct their services and thus attain greater control over their lives.

Section 1
Introduction

As part of the New Freedom Initiative,[1] Congress provided funds for the Systems Change Grants for Community Living program (hereafter, Systems Change grant program) in fiscal years (FY) 2001 through 2006. This initiative is designed to help states and other entities identify and implement methods to increase access to, and the availability and quality of, home and community services. Another major goal of these grants was to increase options for individuals to choose and direct the services they need to live independently in the community and retain control over their lives.

Principles of self-direction and choice are embodied in the service model that has come to be called consumer direction or self-direction, which is an alternative to the traditional model of agency-delivered home and community services. Self-direction provides the opportunity for participants in publicly funded programs to exercise the same choice and control that private-pay individuals enjoy in identifying, obtaining, and managing their services and supports in accordance with their needs and personal preferences.[2]

In 2002, also as part of the New Freedom Initiative, the Centers for Medicare & Medicaid Services (CMS) began the Independence Plus Initiative to use Medicaid funding to promote self-direction of services and supports by persons with disabilities and their families. CMS defines a self-directed services program as "a state Medicaid program that presents individuals with the option to control and direct Medicaid funds identified in an individual budget." The CMS requirements for a comprehensive self-directed services program, or Independence Plus (IP), include the following:

- Person-centered planning—a process, directed by the participant, intended to identify the participant's strengths, capacities, preferences, needs, and desired outcomes.
- Individual budgeting—the total dollar value of the services and supports, as specified in the plan of care, under the program participant's control and direction.
- Self-directed services and supports—a system of activities that help the participant to develop, implement, and manage the support services identified in his or her individual budget.
- Quality assurance and quality improvement—a model that will build on the existing foundation and formally introduced under the CMS Quality Framework, of discovery, remediation, and continuous improvement.[3]

Under the new Initiative, states wanting to implement an IP program had to submit an application for a distinct IP home and community-based services (HCBS-IP) waiver or a research and demonstration (R&D) waiver. HCBS waivers are authorized under section

1915(c) of the Social Security Act (SSA), and R&D waivers are authorized under section 1115 of the SSA.

CMS's Independence Plus Initiative was based in large part on states' experiences in designing programs to increase self-direction. In the 1990s, 19 states implemented Self-Determination projects funded by the Robert Wood Johnson Foundation to advance the principles of self-determination—for example, person-centered planning and the development of individual budgets—specifically targeting persons with developmental disabilities. These projects primarily evolved into Medicaid-funded programs under the section HCBS waiver authority. In addition, the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services funded the Cash and Counseling national demonstration and evaluation project in Arkansas, Florida, and New Jersey.

Independence Plus Grants

In 2003, to further encourage states to offer self-directed services options using the IP requirements, CMS awarded $5.4 million in IP grants to 12 states under the Systems Change grant program: Colorado, Connecticut, Florida, Georgia, Idaho, Louisiana, Maine, Massachusetts, Michigan, Missouri, Montana, and Ohio.

States receiving IP grants could either (1) develop new HCBS or R&D waiver programs and/or amend existing self-direction programs to incorporate IP features; (2) build capacity to strengthen new or existing self-direction programs in any of the IP framework areas; (3) build provider capacity under the self-directed services option; and/or (4) hire personnel to research self-direction program designs or funding opportunities with the expectation of submitting an application for a new IP waiver or amending an existing waiver.[4]

Federal Policy Changes

In 2005, during the grant period, CMS modified the requirements for IP programs when it revised the HCBS waiver application, developing a new template to clarify CMS policies governing HCBS waivers. With the addition of Appendix E, CMS requires states to identify the self-direction elements in the waiver and allows them to request that CMS review the application against IP criteria spelled out in the waiver instructions and technical guidance.[5] States no longer need to apply for a distinct HCBS-IP waiver to offer participants the full range of self-direction options; they may now offer *degree*s of self-direction if they are not yet ready to offer the comprehensive program required for IP designation (e.g., they may offer employer authority to hire/dismiss workers or budget authority for goods and services).

To receive CMS designation as a comprehensive IP program, the waiver would need to include all of the following components: (1) participants have the opportunity to direct some

or all services; (2) all participants live in their own private residence, with their families or in a living arrangement where services are furnished to fewer than four persons unrelated to the proprietor; (3) the service planning process is participant led and person-centered; (4) participant direction is available for most services; (5) the employer authority is available to all participants who can exercise the full range of decision-making authority over their workers, and the full array of supports is available to participants who exercise this authority; (6) the budget authority is offered to all participants who direct their services and participants may exercise complete decision-making authority over the participant-directed budget, and the full array of supports is available to participants who exercise this authority; (7) an appropriate method is used to determine the participant-directed budget; and (8) the program has a separate advocacy function available to participants who direct their services, and this function is performed by individuals or entities that do not provide other direct services, perform assessments or have monitoring, oversight, or fiscal responsibilities.

The Deficit Reduction Act (DRA) of 2005 (effective January 2007) gave states additional flexibility to offer self-directed services.[6] The DRA, under section 6087, authorized Self-Directed Personal Assistance Services (PAS) as a state plan option. Section 6087 was codified as section 1915(j) of the Social Security Act, under which states may choose to disburse cash prospectively to individuals who self-direct their PAS. States may also allow participants to use their individual budgets to purchase items that increase independence or substitute for human assistance, to the extent that expenditures would otherwise be made for the human assistance. (States already have the authority to do this in HCBS and R&D waiver programs.)[7] States may use this new option only in programs that they already offer under their Medicaid state plan or an HCBS waiver.[8]

Under section 1915(i) of the DRA, a state may offer HCBS in addition to personal care services under its Medicaid state plan without having to secure federal approval of a waiver, and states also have the option of allowing participants to self-direct these services. With respect to the new HCBS benefit, the term “self-directed” means such services for the participant that are planned and purchased under the direction and control of the participant or the participant’s authorized representative.[9]

With these new provisions, federal policy now provides states with the authority to implement a comprehensive self-direction program under their state plans, without having to obtain either an HCBS or R&D waiver from CMS.

Study Methods

To gather initial information about Grantees’ IP initiatives, we reviewed summaries of their goals and activities and their annual reports submitted to CMS. We also sought input from

the Systems Change grant program's Technical Assistance (TA) providers and CMS project officers. We then conducted two conference calls, in which all the IP Grantees and the TA providers were invited to participate. Discussion focused on what the IP grant had enabled the states to do that they would not have done otherwise, and challenges or barriers grantees faced in implementing grant initiatives. Most Grantees participated in these calls, and those that could not do so sent e-mail responses.

After gathering initial information, we next prepared discussion guides tailored to grant activities and conducted in-depth telephone interviews from November 2006 through May 2007 with all the grant project directors, and with grant partners and stakeholders identified by project directors in three states. Based on these discussions and other source materials, such as grant-produced reports, we prepared written summaries of grant activities and sent them to each project director to confirm their accuracy. We obtained clarification and additional information through follow-up calls and e-mail. To ensure accuracy, we also sent Section 2—Overview of Grantee Initiatives—to all of the project directors for their final review.

Limitations

The descriptions of the initiatives in this report are not intended to be comprehensive or exhaustive but to provide sufficient context to understand the discussion of the policy and implementation issues.

Organization of This Report

Section 2 of this report describes the major features of the Grantees' initiatives. It also discusses the operational, policy, and other issues that Grantees must contend with as they design, develop, and—in a few states—implement components of an IP program. Section 3 provides our conclusions.

The appendix describes each of the 12 Grantees' initiatives, including self-direction programs offered in their Medicaid state plan and waiver programs prior to receiving the IP grant, their IP grant goals, their progress to date, and the challenges they faced.

Section 2
Overview of Grantees' Initiatives

This section highlights the major features of the 12 Grantees' initiatives. Colorado and Massachusetts finished their grants September 29, 2006, and Georgia completed its grant on March 30, 2007; the other 9 states received 1-year no-cost extensions and were in the fourth year of grant activities during the writing of this report. Eight of these states completed their grants September 29, 2007. Ohio received an additional no-cost extension and will finish by March 29, 2008. Detailed information about each Grantee's initiative can be found in the individual state summaries in the appendix.

Prior to receiving their Independence Plus (IP) grants, 11 of the 12 states had implemented at least one self-direction program; some states had as many as four or five. Most of these programs were offered in home and community-based services (HCBS) or research and demonstration (R&D) waiver programs, but some were also offered in Medicaid state plan and state-funded programs. The populations served by these programs included persons of all ages with all types of disabilities.

For example, prior to receiving its IP grant, Maine offered self-directed services to adults in two Medicaid programs: the Consumer-Directed waiver program for persons with physical disabilities and Consumer-Directed Personal Assistance Services under the state plan. Maine also offered self-directed services through two state-funded programs. Missouri offered the option to self-direct personal assistant services in three waiver programs serving persons with mental retardation and other developmental disabilities (MR/DD). Self-direction has also been available under the Medicaid state plan service to persons over age 17 who have a physical disability, and through the Independent Living waiver, which serves adults aged 18 through 59 with disabilities.

Programs implemented prior to receipt of the IP grants generally allow participants to hire, manage, and dismiss workers but not to control an individual budget. Exceptions include Colorado's Consumer-Directed Attendant Support program and Florida's Consumer-Directed Care Plus program.

At the time of the IP grant announcement, several of the states were already planning to develop programs that would give participants control over an individual budget, thanks in part to aging and disability advocacy efforts, legislative activity in support of self-direction, the success of pilot programs, and the positive evaluations of the Cash and Counseling National Demonstration and Evaluation project. For example, Massachusetts used its FY 2001 Real Choice grant to design and implement a pilot program that provided participants with a flexible individual budget for community-based services and support. With the knowledge gained from the pilot program, the State used its IP grant to design a statewide

self-directed service option for elderly persons and working-age adults with disabilities (excluding mental retardation).

Exhibit 1 lists the overarching goal for each Grantee's initiative and the primary approach the Grantee initially planned for achieving it. Goals include the development of the infrastructure for IP program elements, development of an HCBS-IP waiver application or the amendment of an existing waiver program, and the implementation of an IP program.

Target Populations

Most Grantees are targeting self-direction initiatives to individuals with developmental disabilities (DD), and some states are including other populations as well. For example, Missouri is targeting individuals with physical disabilities or mental illness as well as the DD population, whereas Colorado, Georgia, and Louisiana used the grant to provide or enhance self-directed services for individuals of all ages with all types of disability. Michigan is focusing on participants in the State's mental health and DD service system, but is also providing support for the technical and informational infrastructure that supports self-determination in waiver programs serving other populations, such as older adults.

Five states—Connecticut, Florida, Idaho, Maine, and Ohio—are focusing grant activities exclusively on participants in DD programs. However, Idaho is planning to use the implementation of the new self-direction option in the DD waiver program as a test for the infrastructure and plans to offer it in the future to Aged and Disabled waiver participants. The State is also considering offering a self-directed services options to families with minor children with developmental disabilities and special health needs.

One of the Grantees attributed the strong interest in self-direction among the DD population to the service system's habilitative focus throughout an individual's life and the intense desire among many individuals with developmental disabilities to direct their own lives. For example, the strong advocacy efforts of the Idaho Council on Developmental Disabilities were a major factor leading to the State's decision to support the self-direction concept.

Overarching Considerations When Designing an IP Program

Before designing specific IP program elements, states must first decide which Medicaid authority they will use and whether to create a new program or amend an existing one. They also need to conduct outreach to consumers and other stakeholders to ensure their participation in the design of the IP program elements.

Exhibit 1. Overview of 12 Independence Plus Grantees' Initiatives

Lead Agency and Grant Title	Overall Goal	Primary Approach
Colorado Department of Health Care Policy and Financing—*Colorado Independence Plus Initiative*	Establish an individualized approach to emergency preparedness, backup worker plans, and critical incident management for all current and future self-direction programs.	Develop definitions of critical incidents and emergencies, and expand training activities to include the use of new participant protection tools and mechanisms in Colorado's existing self-direction program and in other waiver programs.
Connecticut Department of Mental Retardation—*Level of Need and Individual Budgeting Project*	Incorporate individual budgets into new and existing waiver programs.	Develop an assessment tool that includes risk screening and methodology for predicting level of need; submit an HCBS-IP waiver application for individuals with mental retardation and amend an existing MR waiver to include individual budgets.
Florida Agency for Persons with Disabilities—*Florida Freedom Initiative*	Help consumers in the State's self-direction R&D waiver program to make changes across a range of life areas, including work, budgeting, asset development, life planning, and self-determination.	Apply for an SSA waiver to enable consumers to work without losing SSI and Medicaid benefits, and develop a training program to ensure that consumers have regular contact with an intensively trained professional.
Georgia Department of Human Resources—*The Georgia Independence Plus Initiative*	Establish infrastructure within the State's HCBS for self-directed services that include person-centered planning, support broker and financial management services, quality assurance, and participant safeguards.	Design the operational functions of self-direction for several waiver programs; develop an IP waiver application and amend existing waivers to incorporate IP components.
Idaho Department of Health and Welfare—*Idaho Independence Plus*	Develop an infrastructure that supports self-directed Medicaid services, including enhanced person-centered planning, a refined fiscal intermediary role, a new support broker role, individualized budgets, and a fine-tuned quality assurance management system.	Conduct a statewide public education and training campaign for consumers and providers about self-direction options; develop a new method to define individualized service definitions; expand community support and service options; and amend an existing waiver using IP standards.
Louisiana Department of Health and Hospitals—*Louisiana's Independence Plus Initiative*	Incorporate self-direction components into all long-term care polices and procedures, including person-centered planning, individual budgeting, financial management services, and participant protections.	Build provider capacity under the self-direction option available to participants in the HCBS-IP New Opportunities waiver implemented in 2003; pilot a consumer-direction option in the state plan Long-Term Personal Care Services program.

(continued)

Exhibit 1. Overview of 12 Independence Plus Grantees' Initiatives (continued)

Lead Agency and Grant Title	Overall Goal	Primary Approach
Maine Department of Health and Human Services—*Supporting Choice and Control for Maine Adults with Mental Retardation or Autism*	Enhance choice and control for adults with mental retardation or autism by offering a broader array of more flexible supports within a philosophy of self-determination.	Submit an HCBS-IP waiver application and develop an implementation plan; ensure that consumers and families have information, training, and support to manage their own services and supports in the new program.
Massachusetts Executive Office of Health and Human Services—*Massachusetts Independence Plus Initiative*	Design key infrastructure components to enable individuals to have flexibility and control of their community services and supports, including person-centered planning, support broker and financial management services, peer mentoring, participant protections, and quality assurance.	Develop an HCBS-IP waiver application, and amend or renew an existing waiver program using the IP standards to increase community options for elders or adults with a disability (excluding mental retardation).
Michigan Department of Community Health—*Michigan's Independence Plus Initiative*	Establish flexible self-directed services in the mental health and developmental disabilities service system that include person-centered planning, individual budgets, financial management services, and support brokers.	Develop an R&D waiver application to provide a cash and counseling (C&C) option to the target population, and amend or renew an existing waiver program using IP standards.
Missouri Department of Mental Health—*Missouri Partnership for Self-Directed Support*	Improve and expand services in the State's self-direction Personal Assistant Services option that is available through 3 MR/DD waivers.	Implement a pilot program to test models for individual budgeting, financial management services, and support brokers; and incorporate successful components into 2 MR/DD waiver renewals.
Montana Department of Public Health and Human Services—*Big Sky Bonanza*	Establish a C&C option for the state plan self-directed Personal Assistance Services program, and expand self-direction options in the Elderly and Physically Disabled waiver program.	Submit an R&D waiver application to facilitate a C&C program and prepare an HCBS waiver amendment; implement a system of individual backup worker plans, a disaster and emergency plan, and an improved incident management plan.
Ohio Department of MR/DD—*Ohio's Independence Plus Initiative*	Identify necessary infrastructure to implement person-centered planning, individual budgets, support broker and financial management services, and participant protections.	Obtain CMS approval of an HCBS-IP waiver, and demonstrate successful implementation in a minimum of five geographical areas.

Selecting a Medicaid Authority

At the time the IP grants were awarded, states typically used the HCBS or R&D waiver authority to implement self-direction programs. Each option has its pros and cons. For example, prior to the expansion of self-direction options under the Deficit Reduction Act (DRA) of 2005, states could not offer an individual budget under the state plan without obtaining an R&D waiver from CMS.

As a consequence of federal policy changes during the grant period (see Section 1), several IP Grantees revised their initial plans concerning which Medicaid authority to use in developing and implementing an IP program and began considering amendments to existing waiver programs to add or expand self-direction options. Ultimately, however, states' decisions were based on a combination of factors: the authority used in existing self-direction options, policy goals, availability of state staff, and political factors.

For example, Idaho already had planned to amend an existing waiver because current participants were strongly advocating for more self-direction options. Amending the existing HCBS DD waiver program, rather than implementing a new one, was also viewed as a way to lessen any perceived threat to providers in regard to their role in the service delivery system. In addition, grant staff believed that policy makers were more likely to support an amendment to the existing waiver that allowed participants to choose between traditional waiver services and self-direction than to fund a new waiver that offered solely self-directed services.

Massachusetts also originally intended to amend its HCBS Elderly waiver program to offer an IP option. However, the State was also developing an R&D waiver application and over time determined that its policy goals would be better served by subsuming the Elderly waiver program (and a Traumatic Brain Injury waiver program) under the planned Community First R&D program. The R&D waiver also gave the State the flexibility to meet policy goals unrelated to self-direction that cannot be achieved with an HCBS waiver, including (1) expanding eligibility for home and community services by allowing higher asset levels, and (2) providing services to individuals who do not meet nursing home level-of-care criteria but who are determined to have needs that, if not met, could place them at risk for institutionalization. Consequently, the State decided not to apply for a separate HCBS-IP waiver but to include an "Independence Plus Option" in the new R&D waiver.

In contrast, Montana initially planned to submit an application for an R&D waiver to enhance the self-direction options currently available to state plan participants. However, with insufficient staff resources to administer an R&D program, the State decided to apply for a new HCBS-IP waiver: the Big Sky Bonanza (BSB) Independence Plus waiver program. The waiver was approved, and the State is operating BSB as a pilot in six counties before

expanding it statewide. Current Elderly and Physically Disabled waiver program participants can choose to enroll in the BSB waiver if they want to use the self-direction option. In response to the pilot's success and changes in CMS policy, the State is considering amending its statewide HCBS Elderly and Physically Disabled waiver program to include the self-direction options offered under the BSB waiver, in part to reduce the administrative costs associated with operating two separate waivers.

Involving Consumers and Stakeholders

The "lesson learned" most frequently cited by the Systems Change Grantees has been the importance of involving stakeholders in the planning of systems change initiatives.[10] Stakeholders include consumers and their families and advocates, community service providers, and representatives of state agencies and other entities that will administer the program. Stakeholders' meaningful participation results in a clear determination of the needs of individuals requiring services and supports, articulates the community's expectations, and develops a collaborative approach to program design that can help achieve consensus. Unless the new program obtains feedback, meets stakeholders' needs, and addresses their concerns, the philosophy of self-direction may not be truly operationalized, which could impede implementation.

IP programs have numerous operational details, and designing them to meet the needs of all stakeholders is a complex process. Grantees engaged in a wide range of outreach activities to ensure consumer and other stakeholder input in the design of their IP programs. They established and used formal task forces or work groups that included consumers, providers, advocates, and state staff who collaborated on designing the new self-direction option. They also implemented education and training activities about self-direction generally and new self-direction options, specifically, to help ensure stakeholder buy-in.

For example, Montana grant staff conducted focus groups with consumers served through existing self-direction options in the state plan and the Elderly and Physically Disabled waiver to gather feedback and input for the design of the new HCBS-IP waiver program. They also had a Native American Coordinator at the Montana Center on Disabilities, Montana State University, lead outreach to Indian Nations and contracted with an Independent Living Center to develop and provide the initial orientation and training about the new program for consumers and providers.

Ohio established three groups to address three levels of policy work: (1) a work team in each of the counties participating in the new HCBS-IP waiver; (2) a statewide collaborative group representing all the participating counties and other stakeholders; and (3) an IP Advisory Committee, which includes persons with the expertise or authority to help

eliminate barriers and establish the infrastructure needed to support implementation of the IP waiver. Members of all three groups helped to design the new waiver program.

Involving all stakeholders and ensuring their buy-in requires a strong commitment. Ohio's grant staff noted that achieving consensus in the MR/DD field required much time and effort. Because the State wanted the IP initiative to be a "grassroots/from the ground up" initiative, numerous stakeholders with very diverse views were involved. To assist in reaching consensus, grant staff contracted with an outside entity—the Center for Self-Determination—to facilitate the meetings and bring a national perspective on self-determination to the stakeholder group.

Designing Specific Independence Plus Elements

At the time of the grant awards, receiving CMS IP designation required four key program elements. Virtually all the states used their IP grants to develop one or more of these elements for a new program or to add them to existing programs, which are discussed below.[11]

Person-Centered Planning

Version 3.4 of the revised HCBS waiver application defines person-centered planning (PCP) as an assessment and service planning process directed by the participant, with assistance as needed or desired from a representative or other persons of the participant's choosing. The process is designed to identify the strengths, capacities, preferences, needs, and desired outcomes of the participant and may include other persons he or she has chosen. The PCP process enables and helps participants to identify and access a personalized mix of paid and unpaid services and supports that assist them in achieving personally defined outcomes in the community.

The IP Grantees promoted PCP primarily through education and training. For example, although PCP has been mandated in the Michigan Mental Health Code since 1996, grant staff noted that misunderstanding and resistance had delayed adoption of the principles and practices. To encourage the use of PCP, Michigan tested models for using independent facilitators in developing person-centered service plans with consumers who wish to direct their services.

Michigan's grant staff also produced a *Policy and Practice Guideline for Person-Centered Planning in Community-Based Long-Term Care,* and they are developing materials for persons with serious mental illness and for local agency staff about PCP and other aspects of self-determination. The IP grant is also being used to encourage the development of employment options as part of PCP, and this work is informed by the CMS Medicaid

Infrastructure grant project intended to reduce barriers to employment for persons with disabilities.

Montana's grant stakeholder group reviewed several states' PCP models before selecting Florida's model as a guide, which it then tailored to fit the new IP waiver program. Many participants thought the program's 8-hour training was overly detailed and the spending plan for services and supports too complicated and repetitive. Some participants already knew what services they wanted in their budgets without having to reiterate long-term life goals. As a result of participant feedback, the State is simplifying the training and the assessment and enrollment process. Grant staff recommended, in retrospect, that other states not "person-center the process to death like we did," that they test the planning process with just a few participants and providers, and that states simplify it before finalizing and rolling it out.

Missouri took a unique approach to the provision of PCP by establishing a PCP facilitator position in addition to a support broker position because the State believed that the two roles required different skill sets. The PCP facilitator role requires a higher skill set, and the new Comprehensive Supports waiver program for persons with developmental disabilities requires PCP facilitators to have a 4-year degree and be credentialed as a qualified mental retardation professional; support brokers do not have this requirement.

Individual Budgeting

Individual budgeting allows States to better match a program's benefits to participants' needs by allowing them to exercise choice and control over a specified amount of funds. As defined by CMS in version 3.4 of the HCBS waiver application, the individual budget amount means a prospectively determined amount of funds that the State makes available for the provision of waiver services to a participant. The individual budget amount may encompass all waiver services or a subset. Some programs allow participants to purchase only personal assistance services and supports (PASS), some allow the purchase of any service the program offers, and others permit the purchase of a wide range of services, goods, equipment, and supplies that promote participants' independence or decrease their reliance on human assistance.

To ensure that individual budget amounts are determined fairly, CMS requires states to specify the basis of the method of determining participant-directed budgets and how it is based on reliable cost-estimating techniques, the factors used that may affect variations in the budget methodology, how the method is applied consistently to each participant, and how information about the budget methodology is made publicly available.

Designing this feature of the IP framework requires states to make numerous decisions, and working out the methodology to determine the budget amount can pose a major challenge.

States must develop methodologies to (1) assess the costs under the traditional system, to which the individual budget is the alternative; and (2) ensure that the budget meets the cost or budget requirements of the specific authority under which the budget is being offered: an HCBS or R&D waiver.[12] (As noted in Section 1 of this report, with the enactment of the DRA-2005, states have two additional authorities by which to offer self-directed services and supports: sections 1915(i) and 1915(j) of the Social Security Act.)

To meet these requirements, some states with R&D programs discounted the budget amount not only as a way to meet the budget neutrality requirement but also to reflect that participants did not receive all their authorized services in the traditional agency-delivered service model. However, such reductions may lock in program problems with underuse of services in the traditional services budget because of a lack of workers and may result in budgets that are inadequate to meet consumers' needs.[13]

In addition to considering these factors, states must also decide (1) which services to include in the budget;[14] (2) whether consumers will have a choice of services to direct; (3) whether consumers will be allowed to keep savings to apply to the purchase of goods and services that can increase independence or decrease dependence on paid help; (4) whether the cost of support broker and financial management services will be paid for as a service out of the individual budget (if the program operates under the HCBS waiver authority) or as a Medicaid administrative expense.

To ensure buy-in for a new program, the process for determining the amount of the budget must be transparent to both participants and providers. If consumers are to enroll in an IP program, they have to believe that the budget determination mechanism is equitable and that they will not receive fewer benefits than in the traditional service system.

States developing individual budgeting mechanisms grappled with other issues as well. For example, Connecticut developed a level-of-need assessment and risk-screening tool and individual budgeting mechanisms, which are being used and evaluated in two new waiver programs developed with grant support. However, moving from capitated program-based MR services to individual budgets presented a major paradigm shift; and consumers, families, and some providers have found it difficult to understand the new system. To address this issue, grant staff are working with the provider community to engender trust and confidence in the funding methodologies by offering information sessions and ongoing communication about systems implementation issues, and by including providers in a work group to address rate modifications. They are also educating consumers and families about the benefits of more flexible supports in the new self-direction paradigm.

Several states are addressing methodological issues. Georgia developed a uniform methodology to calculate individual budgets and then found that the individual budgeting

formula resulted in changes (both decreases and increases) in some individuals' waiver allocations. To ensure continuity of services for current waiver participants transitioning to an individual budget, the State is using a transition process in which historical costs initially contribute more to determining the amount of the individual budget but decrease over time.

Idaho developed a scored assessment tool, modeled after similar tools used in other states, that provides an inventory of individualized needs and a methodology that translates these needs into costs used to determine the individualized budget amount. However, self-advocates did not want their needs to be determined solely by a score, and the DD Council and others demonstrated that the assessment score did not necessarily correlate with individuals' needs. In response, the State developed a process that still uses a score but also includes other factors—such as past service usage, natural supports, and living location and situation—and accommodates exceptions (e.g., individuals with extraordinary costs or occasionally high costs). The State is using this methodology to set budgets for participants who select the self-direction option as well as those who continue to use traditional services.

Michigan found that the nature of services and supports for persons with mental illness poses a challenge to the development of individual budgets. When states offer rehabilitative services in their state plans or in an HCBS waiver program, they often use reimbursement methodologies that combine payment for multiple rehabilitative services performed by multiple practitioners into a single combined rate.[15] The challenge is to develop a method to cost-out the amount of funds available to an individual who wishes to self-direct his or her mental health services in an individual budget.

Another challenge is the often very low "unbundled" individual cost for certain services, such as group therapy. A potential approach to this problem is the development of consumer cooperatives that pool individual funds for several consumers who are working together to directly manage their services. Michigan developed such a model with an FY 2001 Real Choice Systems Change grant and one cooperative is currently operating.

In some states, administrative practices can present challenges to developing methods for calculating individual budgets. For example, in Ohio, 88 county MR/DD boards oversee the State's two waiver programs that are administered by the Ohio Department of Mental Retardation and Developmental Disabilities. Because the programs are operated at the local level, they do not have a single standardized assessment tool to develop a participant's service plan, which CMS prefers so as to ensure comparability in the determination of individual budgets. Consequently, the State has had extensive discussions with CMS to provide assurances that using the same set of core questions for all participants in the IP waiver can ensure comparability in the absence of a standardized tool.

Services to Support Self-Direction

CMS requires self-direction programs to support participants with tasks such as developing a budget and spending plan; hiring, managing, and dismissing workers; and performing fiscal and employer-related functions such as payroll and tax filing and reporting activities. Some participants may be able to handle these tasks with minimal or no assistance, but others may want support to participate in self-direction programs, particularly with employment-related tasks such as paying workers' payroll taxes. The extent and quality of these supportive services can determine whether these participants will enroll and stay in the program.[16]

These supports may be furnished as a waiver service or under another Medicaid payment authority (principally as a Medicaid administrative activity).[17]

Support Broker Services. Support brokers (also known as "independence advisors," "consultants," "counselors," or "case managers" in some programs) provide a range of information and assistance. They help participants to create individual budgets or spending plans, locate employees and resources, and perform other coordination services as needed.

Montana's work group designing the support broker, individual budgeting, and financial management services (FMS) components considered the traditional case management model, which uses a nurse and social work team, to be inappropriate for self-directed services and preferred to use the independent living and PCP philosophy for support broker services. Consequently, the State expanded the provider base for support brokers beyond traditional case managers to include local agencies committed to self-direction principles and the PCP philosophy. The State certified nine community agencies as support broker and FMS agencies, a diverse group including Independent Living Centers, waiver case management teams, and Area Agencies on Aging. Tribal agencies may also become support brokers and FMS providers.

Because Idaho's DD Task Force identified support brokers as key to the program's success, when grant staff learned that some participants wanted to choose from a pre-approved pool of potential support brokers and others wanted to use personal contacts to locate brokers, the State targeted its recruitment and training to facilitate participants' selection of brokers through both mechanisms. Idaho does not allow parents to be support brokers for their own children; however, they can assume this role for other children, and other relatives can be support brokers for related children. Grant staff noted that when family members are used as support brokers, the State needs to ensure that participants are free to make choices about their supports; consequently, as part of the quality assurance process, the State uses participant experience surveys in which many of the questions ask about the person's experience in making choices.

Missouri uniquely gave pilot participants the ability to use a support broker and/or a PCP facilitator or to forego hiring either one. Those hired can be "independent" (e.g., a neighbor or relative), work for an agency, or work for the MR/DD Division as service coordinators who do not make decisions about program eligibility. PCP facilitators and support brokers are considered waiver services and their cost is part of the individualized budget.

Financial Management Services. The HCBS waiver authority does not permit states to make payments for services directly to a waiver participant, either to reimburse the participant for expenses incurred or to enable the participant to directly pay a service provider. Instead, payments must be made through an intermediary organization that performs financial transactions on behalf of the participant. An FMS entity plays this role when a waiver program includes the Employer Authority or Budget Authority option.

When used in conjunction with the Employer Authority to hire and dismiss workers, FMS includes—but is not necessarily limited to—operating a payroll service for participant-employed workers and making required payroll withholdings. In conjunction with the Budget Authority, this support includes—but is not necessarily limited to—performing payroll and tax-withholding functions; processing insurance and individual budget data; tracking over-expenditures or under-expenditures; and preparing monthly budget reports for participants, listing expenditures and balances.

Developing FMS is a complex undertaking. States have to choose among different FMS models to determine what options will be available to participants. For example, the two Employer Authority options that may be made available to waiver participants who direct some or all of their services are (1) the "fiscal/employer agent model," which allows participants to be the employer of record and use a financial management agency to assist with human resources activities; or (2) the "agency with choice model," which allows participants to enter into a co-employer relationship with an agency willing to serve as the employer of record. Missouri implemented a pilot program to test the use of these FMS models in two of the State's MR/DD waivers and participants were offered the choice of fiscal employer agent or agency with choice model.

In addition, states have to determine whether FMS will be furnished as a service paid for out of an individual's budget (in HCBS waivers) or conducted as a Medicaid administrative activity. Finally, they have to make numerous decisions about operational details, such as enrollment and payment processes, and the specific roles and responsibilities FMS providers will assume, such as conducting criminal background checks.

In Massachusetts, financial managers who had previously provided services for consumers in the personal care program had difficulty adjusting to the more intensive service needs of waiver participants served under the FY 2001 Real Choice grant's pilot program. When

designing FMS for the IP option in its R&D waiver application, grant staff believed that the State might need to offer a higher reimbursement rate to compensate FMS providers for the extra time needed to monitor spending plans and make payments/reimbursements.

Some states experienced difficulties in setting up financial management services. Idaho's FMS work group struggled with the tax and legal complexities in developing this IP component, and grant staff described a long and arduous process to secure an FMS provider to handle billing, accounting, and quality assurance responsibilities. The State eventually chose an agency with experience in providing FMS in other states and arranged for FMS to be implemented on a fee-for-service basis that is anticipated to be less than 5 percent of the overall budget.

Georgia's grant staff noted that the State purposely limited enrollment in its new self-direction option to allow time to "work out the kinks" before expanding it. They considered this approach to be particularly important when dealing with new fiscal employer agents, because with a small number of participants, policies can be revised very quickly as needed.

Quality Assurance and Quality Improvement

Quality can be measured by the degree to which services and supports for individuals and populations increase the likelihood for desired health and quality of life outcomes and are consistent with current professional knowledge. Medicaid has a critical role to play in developing Quality Assurance and Quality Improvement (QA/QI) systems that effectively address the assurances of HCBS waiver programs or the requirements of the Special Terms and Conditions of an R&D waiver program, including health and welfare of individuals who are elderly or have a disability or long-term illness. The goal of QA/QI systems is to maximize the quality of life, functional independence, health, and well-being of program participants.[18]

In regard to self-directed service delivery, in addition to the statutory assurances in the HCBS waivers, the new HCBS waiver application discusses backup plans, critical incident reporting and management systems, and quality management systems, which CMS expects states to address in any HCBS waiver application or other application that proposes to offer self-direction or that seeks the IP designation.[19] CMS requirements for Quality Assurance and Improvement (i.e., a Quality Management Strategy) are the same for self-direction and non-self-direction programs. In both the self-directed service and traditional service delivery models, CMS requires states to have systems for conducting discovery, remediation, and quality improvement. Additionally, states must demonstrate how the program meets the CMS assurances (depending on the Medicaid authority used), corrects shortcomings and pursues opportunities for improvements, and measures system performance, outcomes, and satisfaction.

Idaho developed a comprehensive QA/QI plan that monitors quality assurance in every component of the self-direction model, whereas other states focused their efforts on backup plans and critical incident reporting and management.

Emergency Backup. At the time of the grant awards, CMS required states to identify and discuss the potential occurrences that might pose harm to participants, such as a worker arriving late or not at all, and to have an emergency backup plan both to reduce the risk of such occurrences and to address them should they occur. CMS also required states to have in place separate statewide and local systems to address participants' needs if their individual backup plan failed. For example, Florida's R&D waiver program had a local system that included an on-call case manager, with home health agencies and, as needed, Adult Protective Services or Children Protective Services as additional backup.

With the revision of the HCBS waiver application, CMS now requires that an individualized "contingency" or backup plan be established as part of a service plan developed using a person-centered planning process. The focus on individualized planning and risk management means that states are not required to establish a systems response (except for natural and man-made disasters). The decision to emphasize individualized risk assessment and risk management was based on feedback from state officials, program participants, and other stakeholders, who said their experience indicated that individualized backup plans would be more reliable and effective. For example, Colorado conducted consumer focus groups and stakeholder interviews to obtain their input on the development of a statewide emergency backup system. A consensus emerged that an individualized plan of participant safeguards is most appropriate for self-direction programs. (For additional information, see discussion of Colorado's grant in the appendix.)

Such plans must address all risks identified during the planning process and provide alternative arrangements for the delivery of critical services, taking the participant's preferences into account. The arrangements typically include the names and contact information for replacement workers and also contact information for locally available assistance, such as a 24/7 call number or a worker registry.

Six states worked on developing procedures for backup worker plans. For example, Idaho now requires backup plans to specify three ways to get help when the primary support is absent and, if applicable, address community-wide emergencies, such as threatening weather, electrical outages, and other circumstances that may create safety issues or support barriers. Missouri implemented a pilot program that included individual backup plans that designate who is responsible for assigning temporary staff when employees fail to report to work. A system backup process ensures staff coverage for participants and includes staff who are available 24 hours a day to address backup issues. In addition, pilot

participants have the continuing support of a service coordinator who is responsible for monitoring health and safety.

Montana developed an individual risk assessment tool to guide participants through a process of developing plans to reduce risk. Consumers and independence advisors are trained to use the tool as part of the PCP process. The tool is unique to the new IP waiver, but the State is considering using it in the traditional waiver program and the state plan. The State also developed a quality management process to monitor and manage participant health and well-being in the new IP waiver.

Critical Incident Management Systems. Version 3.4 of the HCBS waiver application defines a "critical incident" or event as an alleged, suspected, or actual occurrence of (1) abuse (including physical, sexual, verbal, and psychological abuse); (2) mistreatment or neglect; (3) exploitation; (4) serious injury; (5) death other than by natural causes; (6) other events that cause harm to an individual; and (7) events that serve as indicators of risk to participants' health and welfare such as hospitalizations, medication errors, use of restraints, or behavioral interventions.

One of the challenges in developing a system to prevent and address critical incidents is identifying the type of incidents that will trigger investigation and remediation processes. Although some incidents are always serious and need to be addressed immediately (e.g., physical abuse), a worker not showing up can be an inconvenience in some situations and a life-threatening emergency in others.

A QA/QI report that Georgia produced in preparation for implementing self-direction in the State's waiver programs offers the following definition of critical incidents: "An occurrence or event that causes harm or that interferes with an individual's independence or routine." The report further describes a comprehensive incident management process as having six key elements: (1) prevention efforts, which include backup worker plans; (2) a definition of incidents; (3) reporting requirements; (4) investigation and remediation process; (5) follow-up; and (6) corrective action. Grant staff incorporated a list of critical incidents specific to self-direction into the State's current incident management program.

Colorado originally planned to establish a new statewide critical incident management system and a new statewide emergency backup system for all current and future self-direction programs. However, an assessment of Colorado's current statewide systems found that they were designed for services provided by agencies or institutions and do not meet the needs of participants in self-direction programs for several reasons: (1) state critical incident management systems focus on extreme situations, such as abuse, neglect, and exploitation, that do not include what participants define as critical events (e.g., being threatened by an attendant or left in an uncomfortable or unsafe situation); (2) current

systems are designed for use by professionals such as case managers and state staff, not participants (i.e., participants have not been trained or required to identify and report incidents and they do not control the outcome of critical incident reports); (3) state agencies do not have regulatory authority over attendants in consumer-direction programs; and (4) the systems do not address agency problems that can lead to critical incidents (e.g., restricted hours of operation, worker shortages, and failing to provide backup care).

The consensus from both consumer focus groups and stakeholder interviews was that individualized plans for participant safeguards are most appropriate for self-direction programs. Because the State's self-direction programs already have mechanisms for emergency backup and critical incident management, which have demonstrated a high level of participant satisfaction, the Grantee determined that it was unnecessary to establish a new statewide emergency backup system and a critical incident management system for self-direction programs. However, grant staff, consumers, and stakeholders agreed that improvements were needed to better support participants in both preventing and dealing with critical incidents and in meeting emergency backup needs.

Accordingly, grant staff developed critical incident management tools and individual backup worker plans in text, PDF files, and other electronic media. They are available for single entry point agencies, Independent Living Centers, consumer advocates, and all Medicaid waiver participants who use personal care services. The tools were also incorporated into the training manual of the Consumer-Directed Attendant Support program, and enhanced training modules were developed on topics that included preventing critical incidents, minimizing risk of identity theft and financial exploitation, planning emergency backup, preparing for community-wide disasters, and preparing a health care emergency guide for use in cases of unconsciousness.

One challenge has been finding an independent organization to manage a registry of attendants available around the clock for short-term backup care. A grassroots community group in Colorado offered (during the grant project) to develop and support an attendant registry website to provide information and referral services for persons with disabilities but has not yet done so.

Outreach and Enrollment

Given the major change in service delivery that a self-directed services option entails, the enrollment process requires extensive orientation, education, and training for both participants and providers. Virtually all the states produced materials and conducted outreach activities to educate stakeholders about self-direction and IP principles and to recruit participants for grant-funded pilot programs or new self-direction options in new or

existing waiver programs. Outreach efforts were also directed toward recruiting PCP facilitators and support brokers.

For example, Colorado conducted five statewide regional conferences to inform consumers and other stakeholders about the availability of self-direction options and to conduct training workshops that incorporated new participant protection tools created by the grant project. The conferences led to an increase in case manger referrals to the Consumer Directed Attendant Support (CDAS) program and to a 25 percent increase in CDAS applications. The conferences also generated calls from potential providers and participants for the In-Home Services and Supports program, a self-direction option that is available to participants enrolled in both the Elderly, Blind, and Disabled waiver program and the Children's waiver program.

In Idaho, grant staff and stakeholders believed a concerted effort was necessary to educate the public about the capability of persons with developmental disabilities to self-direct their services, because the traditional service system has been largely provider driven. Using grant funds, the DD Council designed and conducted a 10-day statewide bus tour of 35 communities, using self-advocates, agency staff, Council members, and others to raise awareness about the new self-direction option and to obtain feedback about what is important in a self-directed services delivery system. Educational activities included the use of regional teams of self-advocates to prepare consumers choosing to self-direct their services using a train-the-trainer approach. In addition, with input from Medicaid staff, the Council developed a consumer *Guide to a Self-Directed Life*.

Montana contracted with an Independent Living Center (ILC) to develop and provide the initial orientation and training for participants and providers in the new HCBS-IP waiver program. In the future, regional state staff will be responsible for this activity. In addition, the ILC also developed consumer, support broker, and financial manager training curricula and manuals and conducted training sessions in two pilot areas.

Enrollment Challenges

Self-direction programs may seem challenging—even to participants who want to direct their own services. From the State's perspective, unanticipated problems may pose enrollment barriers. For example, Missouri encountered some difficulties enrolling current waiver participants in its pilot project. Despite the distribution of informational and educational materials about the program, only 33 individuals—aged 8 to 60—enrolled. Several factors accounted for the slow enrollment. First, some individuals need around-the-clock care and families need more than four workers to provide this care. Missouri requires employers with more than four employees to provide workers' compensation insurance, which would have to be paid from the individual budget. The State has not yet been able to

find reasonably priced insurance, and too high a cost could result in a substantial reduction in the funds available for services. Some families have purchased their own workers' compensation insurance. Others have added riders to their homeowners insurance, a practice that could create problems if their insurance were canceled following a claim.

Second, many participants are already using the hire/dismiss option and are satisfied with the services they receive. Transitioning to a new system, which is more complex and entails new responsibilities, is a disincentive for some participants. Third, some waiver participants receive services through multiple programs—and having to manage a budget for just some of the services could also be a disincentive.

Some states choose to limit initial enrollment to give them time to "work out the kinks" and to ensure that all of the program infrastructure is in place and operational. Both Idaho and Montana implemented pilot IP programs to give Medicaid agency staff as well as participants and providers a chance to learn how the program works and to use the pilot experience to modify the program before statewide implementation. Although some consumers are eager to enroll as soon as possible, both states expect enrollment to be slow initially as consumers and providers wait to see how the program is working for others.

Summary of Grantees' Progress

As noted earlier, three of the IP Grantees had completed their grants, and nine were in their fourth year of grant implementation during the writing of this report. Two Grantees did not accomplish goals to submit IP waiver applications—primarily for budgetary reasons—but seven that planned to submit applications for new or enhanced self-direction programs have done so, and an eighth plans to do so in the near future. Five states had their waivers approved, renewed, or amended and have begun implementing their programs. Exhibit 2 summarizes Grantees' enduring systems improvements relating to new self-direction options. For more detailed information about Grantee activities and accomplishments, please see the individual state summaries in the appendix.

Exhibit 2. Enduring Systems Improvements: New Self-Direction Options

State + Original Goal	New Self-Direction Options
Connecticut Submit an IP waiver application for individuals with mental retardation (MR) and amend an existing MR waiver to include individual budgets.	The State received approval for an HCBS-IP waiver, effective February 1, 2005, which introduced in-home, flexible services for children and adults with mental retardation; and replaced its Consolidated waiver in order to add individual budgeting and flexible supports under a Comprehensive Supports waiver, which became effective October 1, 2005.
Georgia Develop an IP waiver application and amend existing waivers to incorporate IP elements.	The State has amended three HCBS waivers to include new self-direction options, including an individual budget for one of the waivers. The State also submitted a renewal application that includes a request for IP designation for one of the amended waivers.
Idaho Amend an existing waiver to incorporate IP elements standards.	CMS approved Idaho's amendment to its HCBS Developmental Disabilities waiver, and, as of February 2007, the My Voice, My Choice option is available as a pilot program to waiver participants in three Idaho communities.
Massachusetts Develop an IP waiver application and amend or renew an existing waiver program using IP standards.	In December 2006 the State submitted the Community First R&D waiver application, which includes an IP option, to CMS.
Michigan Develop an R&D waiver application to provide a cash and counseling (C&C) option, and amend or renew an existing waiver program using IP standards.	The approval for self-directed services within the MI Choice waiver was formally granted for four pioneer sites in October 2006. The State intends to expand to a statewide implementation model on approval of the renewal application for the MI Choice waiver.
Missouri Implement a pilot program to test IP elements and incorporate successful elements into 2 MR/DD waiver renewals.	The State added an individual budgeting option, independent PCP facilitators, financial management services, support broker services, and an individual backup and incident management system to two MR/DD waiver programs. The two waivers were renewed July 1, 2006.
Montana Submit an R&D waiver application for a C&C program in the state plan and prepare an HCBS waiver amendment.	A new HCBS-IP waiver program was approved in April 2006. However, in response to changes in CMS IP policy (see explanation in text), the State is considering amending its Elderly and Physically Disabled waiver to include the same IP features that were in the pilot IP program.

Section 3
Conclusions

Traditional publicly funded home care programs rely on public or private agencies to hire home care workers; schedule, provide, and direct services; monitor quality of care; pay workers and applicable payroll taxes; and discipline and dismiss workers if necessary.[20] In the agency-delivered service model, clients can sometimes express preferences for services or workers but have no formal control over them. This approach to care operates on the assumption that professional expertise and accountability are critical to the provision of good quality care at reasonable cost.

In contrast, the philosophy of self-direction assumes that participants are experts on their own needs and that giving them control over their services will help to ensure the quality of those services. Self-direction programs give participants control over who provides services, when they are provided, what is provided, and how these services are delivered. Typically, self-direction programs allow participants to hire, train, supervise, and dismiss home care workers: the Employer Authority. Some programs also give participants control of an individual budget: the Budget Authority.

This report describes the initiatives of 12 Systems Change Grantees to develop new self-direction programs that embody the principles of CMS's IP initiative. The focus of these grants is program design and development rather than implementation; thus their initiatives generally reflect issues that must be addressed at the beginning of the process.

States receiving IP grants faced numerous decisions and issues in designing their initiatives. First, they had to decide which Medicaid authority to use. Because federal self-direction policy has evolved since the IP grants were awarded, states now have additional options to offer self-directed services. In particular, states no longer need to obtain an HCBS-IP waiver or an R&D waiver to initiate the full range of self-direction options under the state plan or an HCBS waiver.

Second, Grantees recognized that successful design and implementation of a self-direction program, as with all efforts to reform the long-term care system, require the participation and buy-in of key stakeholders, including participants, caregivers, providers, and relevant state agencies. To involve stakeholders and obtain their input, states used multiple approaches, including task forces, committees, and work groups.

Third, a key component of the IP model is person-centered planning, which seeks to shift control of service planning from professional to participant. States noted that education and training are needed, for both current case management staff and participants, to embed this concept into the service system. However, some people may not want to engage in a

complex and time-consuming PCP process in order to receive services. Allowing participants to lead the service planning process and to determine, for themselves, how much information they want to provide about life goals would address this concern.

Fourth, participant control over an individual budget is a key IP element. However, the range of services that participants can direct in their individual budgets varied among states. Some limited the budget to personal care services, others included any service covered by the waiver program, and still others included a broad array of goods and services. Developing methods for calculating individual budgets proved to be a challenge in some states, as was the move from capitated program-based services to individual budgets. Given the challenges, Grantees noted the importance of education and training for both providers and participants to ensure that everyone (1) understands how budgets will be calculated and (2) has confidence that the process is both fair and equitable and that individual budgets will be sufficient to provide needed services.

Fifth, although the basic assumption underlying IP is that participants are capable of making the choices that affect their lives, some people with disabilities need supports to direct their services. To address this need, Grantees worked to establish financial management services and support broker services but employed different approaches for providing these services to address stakeholder concerns and specific challenges (e.g., a shortage of support brokers in rural areas).

Sixth, quality assurance and quality improvement are increasingly recognized as indispensable components of a balanced long-term care system. Quality assurance and quality improvement in the provision of home and community services can be challenging because services are highly decentralized. States have employed a range of approaches for addressing these requirements that other states may find useful.

In conclusion, the activities of IP Grantees are part of a range of activities supported by the Centers for Medicare & Medicaid Services to expand self-direction of long-term care services and supports. Many of the Grantees have already implemented new self-direction options, others are close to doing so, and a few are still developing the infrastructure needed to support self-directed services. Though some have made greater strides than others, all have laid the groundwork for increasing the number of individuals who have the option to direct their services and thus attain greater control over their lives.

Endnotes

[1] In 2001, President George W. Bush announced the New Freedom Initiative to remove barriers to community living for people of all ages with disabilities or long-term illnesses.

[2] Individuals who are paying for services with funds to be reimbursed through a private long-term care insurance policy may have restrictions on their choice and control.

[3] The Centers for Medicare & Medicaid Services. *Independence Plus Overview*. www.cms.hhs.gov/IndependencePlus/. Accessed August 2007.

[4] The Centers for Medicare & Medicaid Services. 2003. Invitation to Apply for "Real Choice Systems Change Grants for Community Living" to Improve Community Services for Children and Adults Who Have a Disability or Long-Term Illness. CFDA No. 93.779 (pp. 33-34).

[5] In 2002, CMS released the Independence Plus HCBS waiver application template. Through the Independence Plus Initiative, CMS identified how participant direction could be implemented within the section 1915(c) HCBS waiver framework and established essential, baseline expectations, including necessary participant protections and safeguards. Several states have used the Independence Plus waiver template to design and implement waiver programs that feature self-direction as their primary service delivery method. When the waiver application met certain criteria, CMS conferred the Independence Plus designation to recognize the state's especially strong commitment to self-direction.

The HCBS waiver application Version 3.4 (released in November 2006) incorporates the principal features of self-direction from the Independence Plus waiver template. The development of the new application benefited from the experience that both CMS and states gained through the Independence Plus Initiative in implementing self-direction programs. CMS encourages the use of the HCBS waiver application Version 3.4 rather than the Independence Plus waiver template to incorporate self-direction options into waiver programs.

CMS will continue to award the Independence Plus designation to recognize states that provide all waiver program participants the opportunity to direct their services and make available to them a full range of supports for participant direction. The waiver application can be found at www.cms.hhs.gov/HCBS/02_QualityToolkit.asp. Source: The Centers for Medicare & Medicaid Services. November 2006. *Application for a §1915(c) Home and Community-Based Waiver [Version 3.4] Instructions, Technical Guide and Review Criteria.*

[6] PUBLIC LAW 109–171—FEB. 8, 2006, *Deficit Reduction Act of 2005*, Section 6086: Expanded Access to Home and Community-Based Services for the Elderly and Disabled, and Section 6087: Optional Choice of Self-directed Personal Assistance Services (Cash and Counseling). The text of §1915(i) and §1915(j), included within sections 6086 and 6087, respectively, is located at http://www.hcbs.org/moreInfo.php/nb/doc/1523/Deficit_Reduction_Act_of_2005.

[7] With respect to goods and services under the HCBS waiver authority, states cannot allow participants to use cash to buy unspecified goods and services. States must create a specific service coverage for goods and services because, under an HCBS waiver, all services have to be authorized in the plan of care, and the plan of care must list goods and services as an authorized service.

[8] To clarify, 1915(j) cannot be used to offer personal assistance in a state that does not already cover personal assistance; it can be useful to think of 1915(j) as a self-direction overlay on top of an existing coverage. Because the definition of "personal assistance services" differs in 1915(j) and 1915(c), the specific services that can be self-directed under 1915(j) will depend on whether 1915(j) is applied to state plan services or 1915(c) waiver services.

[9] In the state plan amendment, states are required to describe the method for calculating the dollar values in such budgets based on reliable costs and service utilization; define a process for making adjustments in such dollar values to reflect changes in individual assessments and service plans; and provide a procedure to evaluate expenditures under such budgets.

[10] The Centers for Medicare & Medicaid Services. *Real Choice Systems Change Grant Program: FY 2001 Nursing Facility Transition Grantees: Final Report*; and *FY 2001 Community-Integrated Personal Assistance Services and Supports Grantees and Real Choice Grantees: Final Report*. www.hcbs.org/files/96/4791/NFTGrantee.pdf and www.hcbs.org/files/110/5451/01CPASSFinalRpt.pdf.

[11] As noted in Section 1, when the HCBS waiver application was revised (version 3.4), Appendix E was added, which outlines the current IP requirements.

[12] The Kaiser Commission on Medicaid and the Uninsured. January 2007. *Beyond Cash and Counseling: The Second Generation of Individual Budget-based Community Long Term Care Programs for the Elderly*.

[13] Ibid.

[14] Within the parameters of the Medicaid authority under which the program operates.

[15] CMS continues to examine policies regarding bundled rates to obtain a better understanding of the component costs of these rates.

[16] The Kaiser Commission on Medicaid and the Uninsured. Op.cit.

[17] The Centers for Medicare & Medicaid Services. November 2006. Application for a §1915(c) Home and Community-Based Waiver [Version 3.4] Instructions, Technical Guide and Review Criteria.

[18] www.cms.hhs.gov/HCBS/.

[19] The waiver application and various technical guidance documents are available for download at www.cms.hhs.gov/HCBS/02_QualityToolkit.asp.

[20] Wiener, J.M., and C.M. Sullivan, Long-Term Care for the Younger Population: A Policy Synthesis. 1995. In *Persons with Disabilities: Issues in Health Care Financing and Service Delivery,* J.M. Wiener, S.B. Clauser, and D.L. Kennell, eds., pp. 291-324. Washington, DC: The Brookings Institution.

Appendix
Description of Independence Plus Grant Initiatives

This section describes 12 states' Independence Plus grant initiatives. Two states—Colorado and Massachusetts—completed their grants in September 2006, and Georgia completed its grant in March 2007, after a 6-month no-cost extension. The other 9 states received 1-year no-cost extensions, and 8 completed their grants on September 30, 2007. Ohio received an additional extension and will finish its grant activities on March 29, 2008.

The descriptions of the initiatives that follow provide a summary of grant activities already undertaken at the time we spoke with the Grantees. They are not intended to be comprehensive or exhaustive but to provide sufficient information to understand the discussion of policy and design issues that Grantees are addressing as well as to understand the challenges and barriers they have faced in designing and implementing self-direction programs.

COLORADO

Prior to receipt of the Independence Plus (IP) grant, Colorado operated two self-direction programs. The Consumer Directed Attendant Support (CDAS) program, which was established through a research and demonstration (R&D) waiver, provides participants who demonstrate a need for home care services with an individual budget for attendant support services and a fiscal intermediary to handle payroll functions. The funds traditionally paid to home health agencies for attendant support are made available to participants instead, based on each person's utilization history or current care plan. Individuals enrolling in CDAS receive training on attendant management and related fiscal management. The CDAS program's goals are to increase participants' independence and self-sufficiency, to improve the quality of attendant support provided, and to decrease state costs for providing attendant services.

The second program—In-Home Support Services (IHSS), which is a new method of service delivery available to clients enrolled in either the Elderly, Blind, and Disabled waiver program or the Children's waiver program—uses an agency with choice model. This model allows participants to recruit, train, and supervise workers who are employed by an agency that handles budgeting and payroll tasks. IHSS agencies are a new Medicaid provider type that offers independent living core services, 24-hour backup services, and contracts with or has on staff a health professional responsible for oversight of attendant training. Attendants selected by clients are employed by an IHSS agency of their choice.

The two programs made self-direction available to many waiver program participants, but the quick push to implement them resulted in a system with little infrastructure. Program experience highlighted the need to develop participant safeguards in keeping with the philosophy of self-direction.

Independence Plus Grant Initiative

The IP grant was awarded to the Department of Health Care Policy and Financing, the state Medicaid agency. Its primary focus was to strengthen and build upon existing capacity to establish a statewide emergency backup system and critical incident management system for all current and future self-direction programs. Colorado has numerous critical incident management systems currently in place, including those administered by the Department of Human Services/Adult Protective Services, the Division of Child Welfare, and the Developmental Disabilities Division.

As part of the research conducted under the IP grant, six focus groups were held statewide, involving a total of 51 participants—46 individuals with disabilities who use attendant services and 5 people who manage the attendant services of a family member. The focus

group consultant produced a report, *Improving Infrastructure: Voices of Attendant Services Users,* that identifies the strengths and weaknesses of the current Colorado long-term care system from the consumer's point of view. The report also specified what to include when defining a critical incident and developing an emergency backup system, and recommended ways to improve the self-direction infrastructure. The focus group final report is available at http://www.hcbs.org/.

Grant staff also conducted 42 interviews with other stakeholders, including current and former staff at the Medicaid agency, the Department of Public Health and Environment, the Board of Nursing, urban and rural single entry point agencies, care provider agencies, urban and rural Adult Protective Services, the Division of Developmental Disabilities, the Division of Child Welfare, and Community Centered Boards, as well as advocates.

The research demonstrated that the State's critical incident management systems were designed for services provided by agencies or institutions and do not meet the needs of participants in self-direction programs for several reasons.

1. The state systems for critical incident management focus on extreme situations such as abuse, neglect, and exploitation, which, although critical, are not inclusive of what consumers define as critical events. Consumers include a wider variety of situations, such as being threatened by an attendant, left in an uncomfortable or unsafe situation, or cared for by an attendant who behaves inappropriately.
2. Professionals such as case managers and state staff use critical incident management systems, but consumers do not have an active role. They have not been trained, nor are they required to identify and report incidents, and they do not control the outcome of critical incident reports.
3. State agencies do not have regulatory authority over attendants in all self-direction programs because the attendants are not always agency employees nor are they required to be certified or licensed. As a result, it would be difficult to impose penalties or sanctions against attendants responsible for critical incidents.
4. The current systems do not address agency problems that can lead to critical incidents. Consumers and their families and advocates often criticize agencies for restricted hours of operation, worker shortages, and failing to provide backup care. As a result, consumers often rely on informal backup care, provided by family, friends, or neighbors, or call 911.

The consensus in both the consumer focus groups and the stakeholder interviews was that an individualized plan of participant safeguards is most appropriate for self-direction programs. Because Colorado's self-direction programs already have mechanisms for emergency backup and critical incident management, which have demonstrated a high level

of participant satisfaction, the Department determined that it was unnecessary to establish new statewide emergency backup and critical incident management systems for self-direction programs.

For example, the CDAS program is a coordinated effort by the participant, case manager, Intermediary Service Organization, and program administrator with many checks and balances. For many CDAS participants, the informal—but reliable—method of backup care becomes formalized in the individual backup plan. Also, the participant defines critical incidents and takes an active role in managing them.

However, grant staff believed that some improvements were needed to better support participants in meeting emergency backup needs and preventing and dealing with critical incidents. Consumers and other stakeholders suggested improvements to the existing CDAS system, such as augmenting consumer training materials with educational brochures, emergency backup decision trees, information on methods to prevent critical incidents, and information on advance directives. They also recommended creating a registry of attendants who would be available for backup care, and conducting outreach activities to educate police officers and firefighters on how to support people with disabilities during emergencies. Such efforts would significantly support participants in self-direction programs while maintaining their independence, choice, and control.

Based on these recommendations and using consumer and peer trainer input, grant staff developed individual backup worker plan and critical incident management tools in text, PDF files, and other electronic media. The tools are available for single entry point agencies, Independent Living Centers, consumer advocates, and all Medicaid waiver participants who use personal care services. The tools were also incorporated into the existing CDAS training manual, and enhanced modules were developed, including those on preventing critical incidents; minimizing risk of identity theft, personal property theft, and legal exploitation; planning emergency worker backup; preparing for community-wide disasters; and preparing a health care emergency guide for use in case of unconsciousness.

Grant staff conducted five statewide regional conferences to inform consumers and other stakeholders about the availability of self-direction options and to conduct training workshops that incorporated the new tools. The participants included 79 Medicaid clients and family members, 74 case managers, 24 provider agency staff, 14 caregivers, 13 advocates, and 42 other stakeholders. Case managers who attended stated that they had gained a greater understanding of self-determination and were considering which of their clients would benefit from using the self-directed services options. The conferences generated calls from potential IHSS providers and participants, an increase in case manager referrals to the CDAS program, and a 25 percent increase in CDAS applications. Peer

trainers began to pilot the modules with new CDAS program applicants during training conducted prior to enrollment.

Challenges

Although the primary grant goals were accomplished, there are still challenges to ensuring participant safety in self-direction programs. Grant staff reported that it has been difficult to find an independent organization to manage a registry of attendants who are available 24 hours per day, 7 days per week, for short-term backup care. After two organizations reviewed the system requirements for managing and maintaining an online registry of attendants, both declined. A grassroots community group offered during the grant period to develop and support an attendant registry website to provide information and referral services for persons with disabilities, but it has not yet done so.

Another difficulty encountered during grant implementation, which illustrates an ongoing barrier to consumers living independently in the community, was the lack of accessible transportation, particularly in rural areas, making it impossible for some consumers to participate in focus groups, meetings, and conferences. Although scholarships were available through the grant to cover transportation, attendant costs, and lodging, fewer consumers requested them than expected. Teleconferencing alleviated but did not solve the problem completely. It was more difficult to communicate information and to identify who was speaking in teleconferences. Although the State has used video-conferencing to train case managers, the equipment may not be in an area that consumers can reach easily.

Establishing a long-term care system that allows consumers rather than professionals to direct services requires a major paradigm shift, grant staff pointed out. Education is needed for some long-term care professionals in the community who are unfamiliar with the self-direction model and may have long-held prejudices regarding the abilities of people with disabilities. The paradigm shift must also be reflected in government policy. Most current rules and regulations were developed when people with disabilities could only receive services in institutions, and new CMS requirements focus on risk management and protection and impose rules used in the agency service model.

To build a system in which consumers have the authority to direct services and control their lives, states need to use a collaborative approach involving all people with a stake in the outcome. They must also provide resources and training that incorporate consumer and peer trainer input to ensure that materials and presentations are effective, useful, and meet consumers' needs.

Outcomes and Enduring Systems Improvements

As a result of the CDAS program's successful implementation and the support of the IP grant and other Systems Change grants, in 2005 the State enacted legislation directing the state Medicaid agency to add an individual budget option for attendant support services to all Colorado HCBS waivers. The State has since implemented a new HCBS waiver for individuals aged 55 or older who are interested in directing their own services—the Consumer-Directed Care for the Elderly waiver—which uses the same individual budget and fiscal intermediary model as the CDAS waiver program. Currently, the Department of Health Care Policy and Financing is not accepting applications for the CDAS program because the implementation of the new individual budget option in the IHSS program that serves participants in the Elderly, Blind, and Disabled waiver program and the Children's waiver program is scheduled for January 2008.

The IP grant enabled the Department to research and develop improvements in Colorado's emergency backup and critical incident management systems to better support self-direction in Medicaid. The backup worker plans and critical incident management protocols developed through the IP grant will be part of the training for the new self-direction option in all waivers. In addition, although the tools were initially designed for participants in self-direction programs, slight wording changes have enabled waiver participants receiving services through agencies to also use these tools.

Grant staff also produced a report—*Improving Emergency Backup and Critical Incident Management for Consumer Direction*—summarizing information gathered from the key informant interviews and consumer focus groups, as well as research on other states' initiatives. The report includes definitions for critical incident and emergency backup, provides recommendations for the Department, and outlines an implementation plan for the recommendations (http://www.hcbs.org/).

CONNECTICUT

Prior to receipt of the Independence Plus (IP) grant, Connecticut had two self-determination programs that included self-direction options: (1) a state-funded self-determination initiative that evolved from a Robert Wood Johnson Foundation grant, which serves children and adults with mental retardation; and (2) the Personal Care Assistance waiver program administered by the Department of Social Services, which serves 698 people with physical disabilities and permits self-direction of personal assistance services only. The waiver is capped and currently has a waiting list.

The state-funded self-determination initiative supported an employer-of-record self-direction option; provided support broker and fiscal intermediary services; and expanded the type of services and supports that the Department of Mental Retardation (DMR) would fund. Experience with this program informed the development of self-direction options in DMR HCBS waiver programs.

Independence Plus Grant Initiative

The IP grant was awarded to the Department of Mental Retardation to develop new individual budgeting mechanisms and resource allocation strategies to be included in a new IP waiver application and in an amendment for the existing MR waiver program. Grant initiatives were targeted to individuals of all ages who receive services through programs administered by the DMR.

After the initiation of the grant, all stakeholders agreed on a two-waiver strategy, and the State subsequently submitted two waiver applications to CMS: (1) a new IP waiver (Individual and Family Supports waiver) that is expected to support 3,693 participants by the end of its third year of operation, and (2) a Comprehensive Supports waiver that replaced the MR waiver that had expired. Both permit self-direction to the extent desired by the participant.

Individual Budgets

Grant staff developed a comprehensive level-of-need assessment and risk screening tool and associated individual budgeting mechanisms to increase equity in resource allocation and to improve risk management in the individual planning process. The tool designates up to eight different levels of support and has an automated report function that provides a summary for the team developing the individual service plan. The State began using the new assessment tool in April 2006 and requires that the level-of-need assessment and risk screening be reviewed and updated annually if needed.

The changes made in the traditional service delivery system—particularly moving from a form of capitated program-based MR services to individual budgets—represent a major paradigm shift; consequently, consumers, families, and providers have found it difficult to understand the new system.

Some providers became concerned about the impact of the level-of-need assessment on their reimbursement, and some families were concerned about its impact on the type of service options that would be available to them. Because of the high demand for services and subsequent waiting list, the use of a "comprehensive supports waiver" to address needs restricted access to more costly group home options, preferred by some families. Although not a direct result of the level-of-need assessment project, the introduction of a supports waiver is a component of broader systems change in Connecticut, and its impact cannot be isolated from the other changes taking place.

Grant staff worked with the provider community to engender trust and confidence in the funding methodologies by offering information sessions and ongoing communication about systems implementation issues and by including providers in a work group to address rate modifications. Provider input was also sought for waiver modifications to be included in the renewal applications for both waivers. Grant staff also worked to adequately support participants and families who choose self-direction and to educate them about the benefits of more flexible supports in the new self-direction paradigm.

A recent lawsuit settlement requires the State to serve 150 individuals on the waiting list each year with an average expenditure of $50,000. Given the State's fixed budget for MR services, it is challenging to serve additional individuals as well as current waiver participants, some of whom are aging and need augmented services. The increased demand combined with the funding limit requires the State to continually forecast expenditures because they can have an impact on the resource allocation methodology and the resulting amount of individual budgets.

Outreach and Enrollment

Grant staff presented information to legislators, consumers, and stakeholders about the opportunities and challenges of self-direction options in Medicaid waivers. They also produced and distributed guides for consumers and families: *Understanding Connecticut's Department of Mental Retardation HCBS Waivers* and *Understanding Your Hiring Choices*. As of spring 2007, approximately 600 participants had enrolled in the self-direction option of the new Independence Plus waiver, and approximately 300 had enrolled in the self-direction option of the new Comprehensive Supports waiver.

Outcomes and Enduring Systems Improvements

The State received approval for an HCBS-IP waiver, effective February 1, 2005, called the Individual and Family Support waiver, which introduced in-home, flexible services for children and adults with mental retardation. The DMR also submitted another waiver application to replace its Consolidated Waiver in order to add individual budgeting and flexible supports under a Comprehensive Supports waiver, which was approved effective October 1, 2005.

Interim individual budgeting methods are in place to support self-direction in both new waiver programs. The State is totally revamping its traditional reimbursement mechanism—moving from a type of capitated funding for limited service options to a fee-for-service (FFS) system that allows participants to choose from a larger service array. Although the FFS system has been fully implemented for new individuals entering the service system, the State has developed a transition plan to move participants supported under the traditional program contract models to the new reimbursement system, which will be implemented throughout FY 2007 and FY 2008.

FLORIDA

The Independence Plus (IP) grant was awarded to the Agency for Persons with Disabilities. Rather than expanding the State's Consumer-Directed Care Plus (CDC+) program, the grant's focus was on enabling individuals with disabilities in CDC+ to become more independent through an asset-development program. Although the CDC+ program is available as a self-direction option for persons of all ages and all types of disability being served by the State's four waivers, only CDC+ participants with developmental disabilities were recruited for the IP grant project.

Independence Plus Grant Initiative

Current income and asset limits for disability benefits and welfare programs in many cases can discourage SSI and Medicaid beneficiaries from seeking employment and accumulating assets for fear of losing their benefits. To address this issue, the grant project secured a waiver from the Social Security Administration (SSA) under section 1902(a)(10)(c)(i) to allow individuals enrolled in the CDC+ program who receive SSI to keep more of their earned income if they work, and to accumulate assets up to $10,000 annually to save toward specific goals. A major grant objective is to determine whether allowing increased asset levels improves individuals' quality of life and helps break the cycle of poverty.

After the SSA waiver was secured, grant staff worked closely with the state Medicaid agency to develop rules allowing increased flexibility in CDC+ budgets. One rule developed for the project allows participants to use up to $1,500 of their budget to develop a micro-enterprise (a small business with fewer than five employees and an initial investment of less than $25,000). Another rule permits the purchase of a vehicle using CDC+ budgets. Participants can save this money from their budget through service efficiencies or the use of natural supports.

Additionally, the SSA waiver permitted SSI participants to have special Individual Development Accounts (IDA) to save for targeted goals without affecting their eligibility for SSI and SSI-linked Medicaid. Unfortunately, the project was unsuccessful in securing an IDA asset waiver for project participants who lose their SSI/1619(b) status and need to apply directly to the State for a Medicaid waiver as a Title II or Disabled Adult Child beneficiary. Consequently, project participants who lost their SSI/1619(b) eligibility during the course of the project were forced to spend down their IDA account to ensure that their total countable assets were less than $2,000 prior to applying for Medicaid through the state eligibility determination process.

Outreach and Enrollment

After an initial attempt to launch the project that resulted in less-than-anticipated enrollment, grant staff determined that participants needed significantly more direct support than planned to participate in the program. To address this need, the original enrollment goal was markedly reduced from 1,500 to a more realistic goal of 50 to 200 participants statewide. Additionally, grant staff ensured that participants had regular direct contact with intensively trained professionals to guide them through the decision making required to expand their control of personal budgets, to build assets, and to make choices that improve their quality of life. The State used general revenues and funds from a Medicaid Infrastructure grant to provide intensive training to grant and other agency staff about work incentives, supported employment, and public benefits.

Grant staff educated support brokers, advocate groups, providers, and policy makers about consumer direction, self-determination, and the broad authority provided under research and demonstration (R&D) waivers, with a specific focus on the SSA waiver of the income and asset rule. They also developed a variety of outreach and educational approaches for recruitment purposes and identified suitable participants for the grant program. However, the grant's already-reduced enrollment goal of 200 statewide proved difficult to achieve. Eligibility was limited to persons with developmental disabilities already participating in the CDC+ program, which has only about 500 working-age participants, many of whom have elected not to work or have very significant disabilities that greatly limit work opportunities. Approximately 35 participants had enrolled as of January 2007.

Challenges

The most significant challenge the program faced was both the real and perceived potential loss of Medicaid eligibility for home and community supports for individuals with disabilities who earn a moderate or high income. Under section 1619(b) provisions, the SSI program offers generous earning limits that permit recipients, in many cases, to work significantly above the default Substantial Gainful Activity level of $900 per month and still retain Medicaid eligibility. The grant project recruited SSI participants, and the program built on this generous income limit that is available to all SSI participants. However, there are several ways in which eligibility for SSI and the section 1619(b) work incentive can be inadvertently lost when individuals enter the workforce.

Some grant project participants lost SSI eligibility and thus needed to qualify for Medicaid under the 300 percent special income rule. The eligibility criteria for the Medicaid and SSI programs interact in complex ways, and in some cases very skilled legal and benefits planning assistance is required to ensure continued eligibility, or to recover lost eligibility. To help ensure that project participants did not jeopardize their Medicaid eligibility, participants who earned income were required to consult with a Social Security-funded

Benefits Specialist/Community Work Incentives Coordinator, and grant staff also received in-depth training on the impact of earnings on benefits.

Florida strongly encourages employment for individuals with disabilities, but, without a Medicaid Buy-in option, the real or perceived threat of loss of Medicaid is a major work disincentive; many potential wage earners who rely on the Medicaid waiver choose to remain on public assistance rather than risk loss of their needed medical supports through working.

State Medicaid agencies do not typically provide detailed counseling on SSA work incentives and thus are not in a position to provide critical guidance regarding maintenance of benefits for working individuals. Persons with disabilities need more information on existing Social Security work incentives, and the State should employ benefits analysts who specialize in the needs of people with significant disabilities who can nonetheless earn income.

Outcomes

The asset-development project was not sustained because SSA allowed the waiver to expire in February 2007. However, project participants can keep their individual development accounts for up to 5 years.

The grant project brought to the agency's attention the critical need to address long-term benefits eligibility issues for all Medicaid eligibles who work, regardless of whether they participate in the CDC+ program. Some state-level DD agencies have developed their own in-house benefits planning capacity, and—if resources permit—the Agency may consider doing so as well.

Based on the experience implementing this project, it is clear that a more comprehensive and sustained program is needed to address the policies and economic conditions that present barriers to increased self-sufficiency for persons with disabilities. The project’s goals may be more realistically achieved through long-term policy and practice changes, and it may be most effective to initially target youth and young adults with disabilities, before they have internalized low expectations for their lives.

GEORGIA

People with disabilities and their families and advocates provided the impetus for the State to adopt self-direction policy by advocating for more choice, control, and flexibility in the long-term care service system. The Governor responded by directing state agencies to work together to achieve these goals. The Independence Plus (IP) grant was awarded to the Department of Human Resources, providing critical support for Georgia's initial efforts to develop, and subsequently implement, a self-directed services delivery system.

Independence Plus Grant Initiative

One of the original goals of the system design portion of the IP grant was to identify which Medicaid authority would work best in Georgia. The grant application proposed that Georgia create a separate self-direction waiver that would serve individuals with all types of disabilities. However, when CMS made the IP designation available under the revised HCBS waiver application, grant staff and the stakeholder committees decided to focus instead on developing self-direction options for existing HCBS waiver programs, to be added when the waivers were renewed.

The recommendations were articulated in a master plan developed under the grant and included the following general observations, as well as specific instructions for completing the new HCBS waiver application: (1) the waivers should be regular waivers, as making them “model” waivers limits the number of recipients to 200; (2) each waiver application should include Appendix E, which addresses participant direction; (3) the waiver programs should be available statewide, not just in certain geographic areas; (4) the waiver-sponsoring agency can choose whether to retain the same target groups and subgroups, or to broaden or narrow the target populations; and (5) the request for IP designation should be made if the waiver application meets the requirements for this designation.

Grant staff developed a collaborative model to design a system of care that includes options for self-direction for persons of all ages with all types of disabilities. Stakeholder committees were formed for each grant initiative and included representatives from the Division of Mental Health, Developmental Disabilities, and Addictive Diseases; the Division of Aging Services; the Department of Community Health; private agencies; community-based agencies and organizations; self-advocates; and family members of waiver service participants.

Using a collaborative approach to plan and develop self-direction policies and procedures across systems serving different populations resulted in a comprehensive design that minimized duplication while allowing for design differences when needed. For example, grant staff and stakeholders found that different approaches to training were required to

address the needs of specific populations. For elderly persons and adults with physical disabilities, training was conducted for case managers who work one-on-one with waiver participants. For persons with developmental disabilities, many people provide services and supports for this population—families, intake workers, peer support—and all received training.

Although the IP grant's overall goal was to produce systems change that supports self-directed, community-integrated living for people of all ages with all types of disabilities, grant initiatives focused particularly on the following HCBS waiver programs:

1. Independent Care Waiver Program for persons with physical disabilities and/or traumatic brain injury.
2. Community Care Services Program for elderly persons and/or those who are functionally impaired/disabled.
3. Mental Retardation Waiver Program for persons with developmental disabilities.
4. Community Habilitation/Support Services for persons with developmental disabilities.

Prior to receiving the IP grant, Georgia did not have a self-directed services option. To make the option available to participants in the four HCBS waivers, the State needed to modify current procedures and processes. For example, items to determine whether participants can "feasibly" direct their services had to be added to the assessment form for determining waiver eligibility. The process for developing plans of care had to be modified to incorporate person-centered planning (PCP), and rules regarding the frequency with which consumers may switch between traditional and self-directed services options had to be developed.

Grant staff and the stakeholder committees addressed these and other issues as they designed key operational functions of the self-directed services delivery system and developed a self-determination master plan—*Master Plan for Self-Directed Care through Georgia's HCBS Waivers*—that incorporates components of the new system and includes processes and protocols for obtaining waiver services. They also produced a report—*Quality Assurance and Quality Improvement* (*QA/QI*) *for the State of Georgia's Self-Directed System of Care*—that recommends adaptations and modifications to HCBS waiver provisions to ensure the health, welfare, and safety of participants in the self-direction system.

Other recommendations from the master plan to assist the State in the transition to a self-directed services system include the following: (1) discuss the individual budget allocation within the PCP process; (2) identify or develop a skills-based tool that evaluates the capacity to hire, supervise, and terminate employees to be administered to participants or their chosen representative; and (3) determine parameters and protocols for switching between traditional and self-direction tracks/waiver programs.

Person-Centered Planning

Grant staff and stakeholders recommended that PCP be standard procedure in all waiver programs, and the State decided that PCP will be used whether a participant chooses a traditional service model or a self-directed services model.

To maximize the effectiveness of a person-centered plan, the process begins immediately following the eligibility determination. The plan of care is developed by the participant and, as appropriate, his or her circle of support (i.e., friends, family, and other community members) with the support broker and others invited by the participant. The plan identifies individuals' needs, preferences, and life goals, and the PCP team prioritizes these needs and goals and identifies all available resources to meet them.

Individual Budgets

One of the grant goals was to develop a uniform methodology to calculate all individual budgets. Grant staff developed a computerized system that incorporated data on past service use and current cost data to use with the formula for calculating individual budgets. They also designed operational procedures and policies, including procedures for budget reviews, modifications, and redeterminations; monitoring, public inspection, and audits; backup; and decisions about unexpended funds.

For some individuals, the methodology resulted in a decrease or increase in their waiver allocations. To ensure continuity of services for current waiver participants who are transitioning to an individual budget, the State is using a transition process in which historical costs initially contribute more to determining the amount of the individual budget but will decrease over time. This process ensures that current waiver participants will not experience a disruption in services when they switch to an individual budget.

Financial Management Services

Grant and agency staff designed a financial management waiver service for participants who choose to self-direct allowable waiver services and established an enrollment and payment process. In addition to providing the financial services, the fiscal agent facilitates a criminal records check on any potential employees before they are hired to work in the self-direction system. The State purposely limited initial enrollment in the new self-direction option to a small number to allow time to "work out the kinks" before expanding the program. This approach was considered particularly important when dealing with new fiscal employer agents because, with a small number of participants, policies could be revised very quickly if needed.

Support Broker Services

Grant staff developed a process to recruit, train, and certify support brokers. Potential support brokers must have a demonstrated understanding of, and commitment to, the tenets of self-determination, person-centered planning, and the Independent Living philosophy. They may have a history of working as a traditional case manager, support coordinator, or care coordinator. Support broker services initially are being provided by traditional case managers. Eventually, the State plans to have independent support brokers (i.e., someone other than a waiver case manager) by making case management services separate from support broker services.

Quality Assurance and Quality Improvement Systems

Grant staff conducted stakeholder meetings and focus groups throughout the State to obtain input on modifications needed in the State's quality assurance and quality improvement (QA/QI) system to enhance the safety of participants in preparation for implementing self-direction in the State's waiver programs. They addressed the issues of critical incident management, emergency backup plans, and hiring practices, as well as the need for education and training for both consumers and direct care workers.

Based on input received, the grant's QA/QI report defined a critical incident as "an occurrence or event that causes harm or interferes with an individual's independence or routine" and identified six key elements of a comprehensive incident management process: (a) prevention efforts, which include backup worker plans; (b) definition of incidents; (c) reporting requirements; (d) investigation and remediation process; (e) follow-up; and (f) corrective action. Grant staff developed a list of incidents specific to self-direction and worked with the State's Information Technology Division to incorporate the information into the current incident management program.

Grant staff also recommended policies and procedures for developing individual worker backup plans to address needs specific to each participant. Even in populations in which individuals have similar disabilities—such as traumatic brain injury—individuals' needs vary considerably. Programs serving multiple disability populations have even more variation. For example, an electrical power outage may prevent meal preparation for most people but will be life-threatening for individuals who use a ventilator. Given the enormous variability in need, emergency backup plans need to address all potential interruptions in individuals' regular routine.

The State already has community emergency preparedness policies that include specific provisions for persons with disabilities. Disability groups and state agency representatives serve on a committee that works on these provisions, and it has been meeting monthly since Hurricane Katrina.

The grant's QA/QI report noted that self-direction promotes personal responsibility over agency liability and that HCBS participants (and their families/circles of support) need ongoing education to prevent incidents that jeopardize their health and welfare. Similarly, workers need education and training to support self-directing participants and their circles of support. The report noted that although orientation training will be provided at enrollment, employee training must be ongoing to be effective. To ensure this, grant staff coordinated with agencies developing a Direct Support Training curriculum in association with community colleges to include training direct care staff on the self-directed services delivery system, and also modified statewide training of peer supporters to include assisting waiver participants and their families to meet self-direction responsibilities.

Outcomes and Enduring Systems Improvements

Beginning in 2005, a total of three waiver programs were amended to add self-direction of personal care services: (1) the Community Care Services Program (CCSP) for elderly persons and/or those who are functionally impaired/disabled, (2) the Independent Care Waiver Program (ICWP) for persons with physical disabilities and/or traumatic brain injury, and (3) the Mental Retardation Waiver Program (MRWP) for persons with developmental disabilities. The MRWP amendment allowed for self-direction of services in addition to personal care services and an individual budget option for these services.

Participants in the three waiver programs who elect to use the new self-direction options will be able to hire their own workers, receive both case management and support broker services from a case manager, and use financial management services. The State plans to eventually have case management and support broker as separate services. These are significant steps toward the State's goal of offering all HCBS waiver participants a self-direction option.

The criteria for participation in the new self-direction options include the following: (1) participant choice, (2) HCBS participant, (3) completed supports assessment, (4) two individual backup plans for each critical service, (5) completion of a health and safety risk assessment, and (6) completion of self-direction training. A supports assessment is completed to determine the participant's and/or his or her circle of support's ability to self-direct services. This assessment is not definitive; for those persons not immediately deemed eligible, a plan for improvement will be suggested to enable them to qualify in the future.

Grant staff designed an enrollment process for the self-directed services delivery system for new waiver enrollees, and also developed a user-friendly flowchart to depict this process and assist participants and families who choose to self-direct. An instructional guide for consumers and support brokers was produced, as was a CD containing the formula, algorithm, and software program for calculating individual budget allocations based on service use and cost data. Enrollment for the new self-direction option began November 1, 2005, for the ICWP and July 1, 2006, for the MRWP; approximately 100 waiver participants

are currently self-directing services. In the MRWP, all individuals (approximately 75) are using the individual budget option and most are also hiring their workers. The CCSP began enrollment July 1, 2007.

The State's experience in implementing self-direction in the three waivers has informed the development of a renewal application for the MRWP, which was submitted to CMS on July 5, 2007, for review and approval and includes a request for IP designation. The waiver, which will be renamed the New Options waiver, will expand self-direction opportunities and includes all the necessary elements for the IP designation.

In addition, the State is amending the Community Habilitation/Support Services waiver program for persons with developmental disabilities who have intensive and comprehensive supports needs to provide an option for them to self-direct most of their waiver services. The amended waiver program will be renamed the Comprehensive Supports Waiver.

Another outcome of Georgia's IP grant project includes a pilot self-determination program for adults with serious mental illness. Grant staff partnered with the Medical College of Georgia to train psychiatric residents in Augusta, Georgia, to utilize Certified Peer Specialists to facilitate self-directed recovery. Additional funding has been obtained to implement and evaluate the pilot, and plans have been finalized for billing peer specialist services provided in the pilot under the Medicaid Rehabilitation Option.

As part of the grant's QA/QI initiative, staff coordinated with agencies developing the Direct Support Professionals Certification Program: a 132-hour certification offered in two 10-week courses followed by a field practicum. Each student uses his or her experiences with a current client with a disability as the field practicum. The program can be taken free of charge by utilizing the HOPE grant, which pays for tuition and supplies.

The Georgia Governor's Council on Developmental Disabilities has thus far certified a number of adult education instructors to teach the courses. The program has been offered at five technical school sites (North Georgia Tech in Clarkesville, East Central Tech in Fitzgerald, and Central Georgia Tech in Macon and Milledgeville, and Athens Tech), and two series of the program have been offered to date. The goal is to offer this program at each of Georgia's 36 technical school campuses, and in the future students will be able to add specialty areas. Workers may later be required to be certified before beginning work, but at present individuals can work while obtaining certification.

IDAHO

Prior to receipt of the Independence Plus (IP) grant, Idaho offered a limited self-direction option under its Aged and Disabled waiver program that allowed recipients of personal assistance services to hire, supervise, and dismiss personal care workers and to use fiscal intermediary services. Because the developmental disabilities (DD) waiver program did not offer any self-directed services and current DD waiver participants were strongly advocating for more self-direction options, the Idaho Council on Developmental Disabilities (hereafter the DD Council) initiated a DD Self-Determination Task Force to move self-direction forward in the State and to work on the development of a self-directed services system.

As a result, in 2002 the legislature directed the Idaho Medicaid agency to apply for a self-direction waiver that would include a pilot program and directed the DD Council to reconvene an expanded Task Force to develop the waiver design. The Medicaid agency and the DD Council worked together to complete the IP grant application to fund the development and implementation of a self-directed services system for persons with developmental disabilities.

Independence Plus Grant Initiative

The Medicaid agency collaborated with several work groups of the DD Council's expanded Task Force to develop different components of the new self-direction waiver. The Task Force included self-advocates and family members; two state legislators; private providers; staff from the Governor's office, Independent Living Centers, and the University Center on Disabilities; and representatives from the Departments of Health and Welfare, Education, and Vocational Rehabilitation, and the Idaho State School and Hospital.

Grant staff noted that the value of involving self-advocates in the design and development of the program from the outset cannot be overstated. Supporting consumers to be meaningfully involved discourages the spread of inaccurate information about the new program, reduces the apprehension of some stakeholder groups, and helps to ensure the development of a user-friendly program.

Based on the Task Force's recommendation, the Medicaid agency decided not to apply for a new waiver but to amend its existing HCBS DD waiver program to include the IP design features of person-centered planning (PCP), individual budgeting, financial management services, support broker services, and participant protections. Amending an existing waiver rather then implementing a new one was viewed as a way to lessen any perceived threat to providers, who might see the new program as having a potentially negative impact on their role in the service delivery system. In addition, policy makers were more likely to support

an amendment to the existing HCBS waiver program that allowed participants to choose between traditional waiver services and self-direction than they were to fund a new waiver.

Person-Centered Planning

Grant staff focused on developing a PCP process that identifies participants' needs and life goals. To support the process, the DD Council in partnership with grant staff created a sustainable training program to help the State move from the traditional service model that uses Medicaid service coordinators to a self-direction model that uses support brokers and a self-directed circle of support (i.e., informal caregivers such as family and friends who volunteer to share responsibility in providing support to the individual and who participate in the PCP process). The training program also familiarizes participants with the planning workbook (a tool used during the PCP process that provides information for individuals to evaluate their needs and risks) and the support and spending plan that outlines participants' personal goals and needs and describes how they will be able to live safely in the community within the allocated budget. The information discussed during the PCP process is incorporated into the workbook, which is submitted along with the support and spending plan to the regional state staff for their approval as part of the waiver enrollment process.

Individual Budgets

Idaho developed a scored assessment tool, modeled after similar tools used in Wyoming, Ohio, and Minnesota, which provides an inventory of individualized needs and a methodology that translates these needs into costs used to determine the individualized budget amount.

However, self-advocates did not want their needs to be determined solely by a score. The DD Council and other advocacy organizations demonstrated that the assessment score did not necessarily correlate with participants' needs. In response, the State developed a budget determination process similar to Wyoming's Doors model. The assessment process still uses a score but now includes other factors—such as past service usage, where a person lives, natural supports, and living situation—and accommodates exceptions; for example, individuals with extraordinary costs or occasionally high costs. This methodology is used to set budgets for participants who select the self-direction option as well as those who continue to use traditional services.

The State plans to continue evaluating the model by determining the volume of participants with historical expenditures that differ from their individual budget. Currently, if the calculated budget varies by more than 5 percent from the previous year's budget, the authorized budget will be that of the previous year even if that amount is higher. During initial implementation, higher budgets are reviewed quarterly to determine whether a budget methodology change should be considered.

Financial Management Services

The grant's financial management services (FMS) work group struggled with the tax and legal complexities in developing this IP element. Grant staff described a long and arduous process to secure an FMS provider to handle billing, accounting, and quality assurance responsibilities. The State eventually chose an entity with previous experience in providing FMS in other states, and arranged for FMS to be implemented on a fee-for-service basis.

Support Broker Services

Idaho's DD Task Force identified support brokers as key to the success of the program very early in the design process. When grant staff learned from potential participants that some wanted to choose from a pool of support brokers and others wanted to use personal contacts, the State targeted recruitment and training to facilitate participants' ability to select brokers either way. An online training program for support brokers that includes videos of individuals and family members talking about best practices in support broker services is available on the Department of Health and Welfare website.

The curriculum offers six modules (self-direction, support broker roles and responsibilities, person-centered planning, skill set needed, ethics and professionalism, and resources) and is available online to facilitate training and encourage the provision of support broker services in rural communities. Grant staff noted that support brokers are expected to "think out of the box" and be creative with natural and paid supports by utilizing nontraditional service providers and community resources.

The State is encouraging Medicaid service coordinators to become support brokers—although their expertise will need to shift because the scope of work is specific to participants' needs and focuses on developing a plan that provides for more flexible nontraditional supports. The program allows parents to be certified providers of personal care services for their own children but not support brokers. However, parents can be support brokers for others' children, and other relatives can be support brokers for related children. Grant staff noted that when family members are used as support brokers, the State needs to ensure that participants are free to make choices about their supports. To implement this, the State is using participant experience surveys as part of the quality assurance process, in which many of the questions ask about the person's experience in making choices.

Quality Assurance and Quality Improvement Systems

Idaho developed a comprehensive QA/QI plan that monitors quality assurance in every component of the self-direction model. Grant staff developed processes to ensure that planning is person-centered and based on choice, there is a process to transition back to the traditional waiver service model if needed, there are methods to identify risks, and there is

a backup plan for supports needed to ensure health and safety. The State requires that backup plans specify three ways to get help when the primary support is absent.

Backup plans may also address community-wide emergencies, such as threatening weather, electrical outages, and other situations that can create safety issues or support barriers. In addition, Idaho has developed a statewide critical incident reporting system, which includes training for consumers on how to file complaints. All participant materials have been developed with input from the DD Council and self-advocates to ensure that they are user friendly.

The State will monitor quality through a quality council for self-direction, and quality management tools will include risk assessments, participant and provider surveys, provider reporting, program observation, and focus groups. The State has set up data collection and analysis mechanisms.

Idaho's state legislature approved self-direction rules and regulations that allow individuals to waive criminal history background checks under certain circumstances (e.g., for chore services and outdoor work, or when services are provided by known relatives). Although this provision raised much concern among stakeholder groups, to stay true to the principles of self-determination and individual choice and control, the State decided to retain the criminal background check waiver in the final program design. However, the criminal background check waiver form guides the consumer to assess risks and to identify safety plans to mitigate those risks. In addition, the support broker must sign the form and confirm that the risks have been discussed and accepted by the participant. The Grantee noted that participants' training emphasizes the value of having a criminal background check for community support workers as a method to help ensure safety.

Outreach and Education

Grant staff and stakeholders believed a concerted effort was necessary to educate the public about the capabilities of persons with developmental disabilities because the service system has been largely provider driven. The DD Council provided information in a variety of ways to waiver participants and their families, to advocates, and to service providers.

Using grant funds, the DD Council designed and conducted a 10-day statewide bus tour of 35 communities, using self-advocates, agency staff, DD Council members, and others to raise awareness about the new self-direction option and to obtain feedback about what is important in a self-directed services delivery system. The Council also produced a 20-minute video documentary about self-direction in Idaho and developed two public service announcements (PSAs). The Council will collaborate with the Medicaid agency to have the PSAs aired on local television stations to promote the new program as it is implemented.

Educational activities included the use of regional teams of self-advocates to deliver the training curriculum, using a train-the-trainer approach to prepare individuals choosing to self-direct their services. In addition, the DD Council developed a consumer *Guide to a Self-Directed Life* with input from Medicaid staff. To evaluate its effectiveness, regional self-advocate teams reviewed the guide and conducted a focus group for individuals with developmental disabilities who had no prior exposure to the self-direction concept.

Challenges

Grant staff and stakeholders described several challenges in the design and start-up phase of the self-direction pilot, as well as challenges they expect to face during implementation. Some providers have difficulty accepting expanded self-direction options, and, in particular, question the viability of a circle of support for certain clients. To address this issue, Medicaid administrative staff have presented provider trainings in each of the three start-up regions to help both traditional and nontraditional providers to better understand the concept of self-direction. However, in some cases, providers have told individuals and their family members that they are incapable of self-directing; thus getting accurate information to individuals in this situation is a continuing challenge.

Recruiting a sufficient number of support brokers has also been a challenge. Despite advertising through state venues, colleges, and the Medicaid agency, and providing training for families and legal guardians, only two support brokers enrolled initially. However, there are currently nine persons who have passed the support broker exam. Recognizing that Idaho is a rural state and that resources and supports may be unavailable in some areas, the State anticipates a small proportion of waiver participants to shift to self-direction. Given this, support brokers might be unable to work full time until the caseload grows, making recruiting even more challenging.

As described earlier, developing a statistically valid model to determine individual budgets was a challenge, as was finding FMS providers to serve the DD population.

Outcomes and Enduring Systems Improvements

CMS approved Idaho's amendment to its HCBS DD waiver, and the *My Voice, My Choice* self-directed services option is available as a pilot program to waiver participants in three Idaho communities: Pocatello, Boise, and Moscow. Enrollment and service authorizations began in February 2007. Initial participation was slow, but interest continues to increase and currently five people are enrolled and receiving services. The State used its 1-year no-cost extension for the IP grant to evaluate the pilot program.

The State will use the initial implementation in the DD waiver program to test the infrastructure and intends to offer the expanded self-direction option to Aged and Disabled

waiver participants in the future. Although DD waiver participants aged 18 and older are the target population for the new self-direction option, the State is also considering offering the option to families with minor children with developmental disabilities and special health needs. The State is working with the Idaho DD Council and other stakeholders to identify a possible framework for this type of service, and although this population is not currently served in a distinct waiver program, the State may consider doing so in the future.

An unanticipated positive outcome of the IP grant project was the formation of the Idaho Self-Advocate Leadership Network. The original purpose of the network was to provide a forum for self-advocates involved in the grant project. As the groups of regional self-advocate teams became active, they decided that they wanted their own organization and established the network. The network is continuing its training activities and beginning to take a stronger role in policy development.

LOUISIANA

Prior to receipt of the Independence Plus (IP) grant, Louisiana had a New Opportunities Waiver (NOW) for adults and children with mental retardation and other developmental disabilities, which allows participants to direct an individual budget for personal assistance services, with the assistance of a fiscal agent, and to hire and supervise workers. This program is currently the State's only self-direction option.

Independence Plus Grant Initiative

The IP grant was awarded to the Department of Health and Hospitals. Its primary purpose is to incorporate the self-determination philosophy into all long-term care programs in the State and to pilot a consumer-directed services option in the Medicaid state plan long-term personal care services (LT-PCS) program.

Grant staff analyzed policies and procedures for HCBS waiver programs, for the Program for All-Inclusive Care for the Elderly (PACE), and for the LT-PCS program to determine what revisions are needed to incorporate self-determination and to remove any barriers to self-direction. They also conducted consumer surveys to obtain input on program features that currently present barriers to independent living and surveyed support coordinators and service providers for their input as well. Once the survey work is completed, grant staff will recommend needed regulatory and rule changes.

Staff worked to develop program policies for assessing the adequacy and practicality of backup plans. They also researched computerized backup systems, such as the one South Carolina uses in its self-direction program, which monitor workers' arrival and departure through a phone system. The State is considering purchasing a similar system. Because the State's Systems Transformation grant is also addressing information technology issues, grant staff were working to coordinate both grants' efforts in this area.

Grant staff also worked to improve the critical incident management system for the State's three waivers—NOW, Elderly and Disabled Adults (EDA), and Children's Choice (CC)—as well as the LT-PCS program and the PACE program. They also assessed different methods to ensure that clients' vital information would be accessible in an emergency evacuation.

One of the grant's objectives was to establish a revolving loan fund to help consumers become self-employed. Grant staff collaborated with Senior Corps of Retired Executives and the Louisiana Small Business Development Center to develop business plan forms, developed informational materials about the application process, and began planning an informational seminar for interested consumers. Grant staff also worked to expand opportunities for NOW, EDA, CC, PACE, and LT-PCS participants to earn income through self-employment, thus increasing their ability to address unmet needs.

Challenges

Recruiting consumers to participate in the IP Advisory Committee meetings, even by conference call, proved difficult, and grant staff struggled to get a representative group to actively participate and attend meetings. To address this problem, the recently conducted consumer survey asked those interested in serving on the Committee to provide contact information, and 123 individuals responded, providing a pool of consumers from which to draw.

Outcomes and Enduring Systems Improvements

By the end of the grant period, the State had developed the infrastructure for a self-directed services option for participants in the LT-PCS program for elderly persons and adults with physical disabilities. The State may consider options to use the new provisions in the Deficit Reduction Act.

MAINE

Prior to the Independence Plus (IP) grant, self-directed services in Maine were available to adults in two Medicaid programs: the Consumer-Directed waiver program for persons with physical disabilities and Consumer-Directed Personal Assistance Services under the state plan. Maine also offers self-directed services through two state-funded programs.

Independence Plus Grant Initiative

The IP grant was awarded to the Department of Behavioral and Developmental Services. Its primary purpose was to assist the State in preparing and submitting an HCBS IP waiver application for adults with mental retardation or autism in order to offer a broader array of more flexible supports based on the self-determination philosophy. The grant project was also developing educational materials and training to ensure that consumers and their families know how to manage their own services and supports.

Maine was also awarded a Systems Change Money Follows the Person grant, which is supporting development of a new system of published reimbursement rates for services and a resource allocation protocol to work in conjunction with the services planning process to determine individual budgets for future HCBS-IP waiver participants.

Some individuals are unable to manage all of their supports, so grant staff are working to develop policies for individuals to have representatives assist them. Because this is a fairly new issue for the State, grant staff formed a work group that included individuals with disabilities, family members who are guardians, key disability-related organizations that frequently deal with guardians and guardianship issues, legal staff, and key state representatives.

After carefully reviewing the State's guardianship policies and processes for adults with developmental disabilities, the work group concluded that many guardianship issues are too complex for them to resolve. Nonetheless, they decided that no individual should be excluded from the benefits of self-directing his or her services and have continued to work on some issues related to using representatives, such as how to avoid a conflict of interest when a participant wants one person to serve as both representative and direct care worker.

Grant staff worked with the grant's advisory work groups to develop a consumer and family training package on several topics, including person-centered planning, management of personal budgets, being an effective employer, and selecting and working with support brokers and fiscal employer agents. They also worked to develop training curricula for support brokers that specifically address distinctions between support broker and case management services. The work groups comprised people with developmental disabilities;

people with physical disabilities who currently self-direct their services; parents; and direct support professionals who together created, reviewed, edited, and clarified materials.

The final presentation of materials will be a co-instructional model with self-advocates playing a major role in training to ensure the inclusion of the consumer perspective. Even though the State is not going to submit the planned HCBS-IP waiver application at this time, many of these materials can still be used by individuals with mental retardation and their families who want to direct their supports (e.g., people aging out of Individuals with Disabilities Education Act funding).

Challenges

It is a continuing challenge to ensure that the program meets the needs of the target population—adults with mental retardation or autism—and that training materials are clear and understandable to those with developmental disabilities. The grant work groups reviewed many currently available training-related materials and found that they are geared toward staff—not participants. The grant's goal was to build a program for participants so that they themselves can use the materials to learn how to direct their services.

Reaching consensus was difficult in developing policy for using representatives and/or guardians to help individuals who are unable to self-direct. Grant staff expanded the group working on this issue to include key individuals who work with adults other than those with mental retardation, for example, elderly persons with dementia or individuals with serious mental illness. The State's Systems Transformation grant will continue to address this issue.

Completing the IP waiver application remains a challenge. Numerous new systems within a restructured department (including both personnel and new electronic data management systems) need to be coordinated when developing a new program. This challenge coupled with the lack of funding for the program has led the State to put the development of an HCBS-IP waiver on hold.

Outcomes and Enduring Systems Improvements

Grant staff have initiated a new way to engage people with developmental disabilities in project development and are in the process of documenting this process so as to involve stakeholders in other grant activities and policy developments. Even though the State is not submitting the HCBS-IP waiver application at this time, the training material developed through the grant will serve as a model for various activities in the State, including agency staff training, guardianship training under the Systems Transformation grant, and developing training and forums under the Medicaid Infrastructure grant to educate people with developmental disabilities about employment changes in the State.

MASSACHUSETTS

Since the 1970s, Massachusetts has offered a self-direction option for Medicaid state plan personal care assistance services, which allows consumers to hire and dismiss their personal care workers and to use fiscal intermediary services. There is also a level of self-direction in smaller state programs, including a Department of Mental Retardation pilot program and a program with the Massachusetts Rehabilitation Commission.

Prior to receiving the Independence Plus (IP) grant, the State used a 2001 Real Choice grant to design and implement a pilot program testing the use of a flexible individual budget for community services and supports with MassHealth participants—both elderly persons and working-age adults with disabilities.

During the Real Choice grant period, the State was engaged in a planning process for home and community services that identified self-direction as a key area for future development. Subsequently, when CMS released the IP grant Solicitation, the State decided to apply for the grant to design a self-direction option for adults with disabilities building on the knowledge gained from the Real Choice pilot program.

Independence Plus Grant Initiative

The grant's primary purpose was to build on the State's current self-direction program infrastructure to meet federal expectations for an IP waiver. The State intended to develop a new HCBS-IP waiver application or to amend an existing waiver to be submitted to CMS no later than the third year of the grant.

However, the State was also developing a research and demonstration (R&D) waiver and over time determined that its policy goals would be better served by subsuming the Elderly waiver (and a Traumatic Brain Injury waiver) under the planned Community First R&D waiver, which will also include adults under age 65 with disabilities (excluding mental retardation). Consequently, the State designed the R&D waiver to include an "Independence Plus Option."

The R&D waiver provides the flexibility to meet policy goals not possible with an HCBS waiver, including (1) expanding eligibility for home and community services by allowing higher asset levels, and (2) providing services to individuals who do not meet nursing home level-of-care criteria but who are determined to have needs that, if not met, could place them at risk for institutionalization. Massachusetts submitted the R&D waiver application in December 2006 and is awaiting CMS approval.

Massachusetts used the Consumer Planning and Implementation Group established under its Real Choice grant to involve consumers in the design of the self-direction option for the Community First Demonstration.

Individual Budgets

Grant staff reviewed the published literature on individual budgeting and researched other states' approaches to determining the amount of individual budgets.

Financial Management Services

In Massachusetts financial managers who had previously provided services for consumers of personal care services had difficulty adjusting to the more intensive service needs of waiver participants served under the Real Choice grant's pilot program. When designing financial management services (FMS) for the IP option in its R&D waiver application, grant staff suggested that the State might need to offer a higher reimbursement rate to compensate FMS providers for the extra time needed to monitor spending plans and make payments and reimbursements.

Support Broker Services

When developing the support broker service for the R&D waiver application, the State built on the knowledge gained from its Real Choice grant's pilot self-direction program. Grant-funded reports on the pilot program described the strengths and challenges of support broker services, and made recommendations for a support broker training curriculum. Based on the pilot, the State now has a better understanding of the challenges traditional case managers may face as they move into a support broker role and the training curriculum needed to ensure the implementation of an empowerment model.

Support brokers are generally drawn from staff of existing provider agencies or have been identified by a client, which means that they have different levels of experience. Family members have assumed this role for some participants, but not all have continued in it, most likely because of the time involved and their other responsibilities and needs as caregivers. Whatever the support brokers' background, training requirements in the new R&D waiver self-direction option will ensure that they understand program guidelines and the meaning of self-direction, and that they will be able to identify and provide the necessary type and level of support.

Quality Assurance and Quality Improvement Systems

Massachusetts designed and created the infrastructure for the necessary components of a quality management system for the self-direction option in the R&D waiver application, as well as the methods to ensure a consumer focus in quality management. Grant staff formed

a work group on quality management that included members of the Consumer Planning and Implementation Group in addition to other community and state partners.

Staff also used a consumer-driven participatory action research group to help develop the quality management system for the IP components of the R&D waiver application. The work group developed recommendations for quality outcomes and measures as well as procedures for emergency backup, critical incident management, and reporting complaints.

Massachusetts developed several levels of backup systems in response to CMS requirements at the time. In the pilot, participants were required to identify a backup worker for each directly hired worker. In addition, one of the pilot's support broker agencies contracted with a home health agency to provide agency-based backup workers as needed. However, the evaluation of the pilot program found that the agency-based system was not utilized, so the State may not renew the contract for it, particularly because CMS subsequently dropped the requirement for a statewide emergency backup system.

Outreach and Enrollment

The grant, in collaboration with other Massachusetts Systems Change grants, supported annual forums to educate the public on the systems change work in Massachusetts and to seek increased stakeholder involvement in grant activities. Consumers and state agency staff worked with grant staff to plan the forums.

The primary mechanism for involving individuals with disabilities in the design and implementation of a self-direction option for the new R&D waiver application was the Consumer Planning and Implementation Group (CPIG) established under the Real Choice grant, which met quarterly under the IP grant. The Collaborative Team (a subset of the CPIG and state agency partners) served as the decision-making entity for the IP grant and met periodically to review documents and provide feedback.

The IP grant funded the development of a DVD documenting the involvement of the CPIG, titled *When CPIG's Fly: Consumer Involvement in Systems Transformation*, and a companion report, *CPIGs Fly: Stakeholder Involvement within the Massachusetts Real Choice and Independence Plus Grants*. Although the CPIG has not been sustained since the IP grant ended, the grant's Collaborative Team meetings will continue. Members of the former CPIG and the ongoing Collaborative Team continue to participate on the Systems Transformation grant steering committee and subcommittees.

When the State drafted the new R&D waiver concept paper, public meetings were held in two areas of the State to explain the new program, including the IP option, and to obtain and respond to public comment. The Grantee also helped facilitate related state policy

meetings with staff from different state agencies; the IP option was one of several long-term care issues discussed.

Consumer involvement in grant activities helped to ensure that the new IP option was designed to meet consumers' needs within the state and federal parameters. Additionally, grant outreach activities have led to increased (1) stakeholder involvement in systems change activities, (2) collaboration among Massachusetts systems change and related initiatives, and (3) consumer and state collaboration on systems change.

Grant staff stressed the importance of building trust between the State and stakeholders. Prior to the Real Choice and IP grants, there was limited dialogue and few in-person discussions about substantive issues. They also noted the advantage of having a consumer involvement mechanism—in this case, the CPIG—in place at the outset of the IP grant, which helped to build trust early in the process. Accommodations such as transportation, stipends, and large print and Braille materials should be provided to ensure accessibility.

Challenges

It was difficult to ensure that IP grant activities were coordinated with the Community First R&D waiver application development activities. Another complexity was ensuring that the design of the IP option was compatible with other provisions in the R&D waiver. The development of the waiver concept paper and waiver application took a long time and needed significant levels of buy-in both in the Office of Medicaid and among stakeholders outside the Office. To address this challenge, grant staff participated in weekly meetings with the development staff for the R&D waiver application.

Based on experiences implementing the Real Choice pilot program, grant staff reported some concerns about how the IP option in the Community First waiver will be implemented statewide. They believe that existing local organizations may lack experience implementing the support broker and fiscal intermediary services, and training will be crucial. Adequate orientation for participants will be equally important.

Outcomes and Enduring Systems Improvements

The State submitted the Community First R&D waiver application, which includes a self-direction option titled "Independence Plus Option," to CMS in December 2006.

MICHIGAN

Michigan's Self-Determination Initiative began in 1997, with support from the Robert Wood Johnson Foundation's (RWJF) National Program on Self-Determination for Persons with Developmental Disabilities. Although there is no legislative mandate for self-determination, person-centered planning (PCP) has been mandated in the Michigan Mental Health Code since 1996. This same Code also offers the option for consumers to obtain a voucher to purchase their services directly, on approval of the local Community Mental Health Services Program director. In addition, Michigan has had a participant-directed personal care program in operation since 1969—Home Help—which has been financed through the Medicaid state plan since 1981. The State was awarded a Cash and Counseling grant from the RWJF in 2004 to implement an individual budget option in the MI Choice HCBS waiver program.

Independence Plus Grant Initiative

The Independence Plus (IP) grant was awarded to the Department of Community Health. Its primary purpose was to develop within the mental health and developmental disabilities (DD) service system a comprehensive capacity to give consumers a high level of choice and control over planning, selecting, directing, and purchasing needed services and supports. The grant objectives also include providing support for the technical and informational infrastructure that supports self-determination for participants in the combined 1915(b) and (c) Managed Care Specialty Supports waiver, the HCBS Children's waiver, and the HCBS Elderly and Disabled waiver (called MI Choice).

One of the grant goals was to plan and develop the infrastructure for a research and demonstration waiver to offer individuals with disabilities the option to receive and direct a cash allotment in lieu of receiving services and supports through traditional methods. The goal was dropped because of a lack of state resources to do the technical work required for the waiver. Grant funds were reallocated to expand training in PCP in the long-term care system and to expand the contractual structures supporting self-determination in the MI Choice waiver program. Consultation, resources, and training were provided by grant staff to mental health service providers and Community Mental Health Programs that had been slow to implement self-determination arrangements.

Grant staff worked to develop a standardized model for participant-controlled provider services arrangements, which includes fiscal intermediary services and methods for determining individual budgets in Michigan's mental health and DD service system. Staff also developed and tested models for participant-controlled long-term care services provided to elderly persons and persons with physical disabilities. In both service systems,

these models include independent facilitators for PCP and the option to use independent support brokers.

To support all the target populations, grant staff drafted new technical assistance materials on the following topics: working with fiscal intermediaries, introduction to self-determination for consumers and allies, hiring staff, and a policy and practice guideline for PCP. The guideline's purpose was to define the use of PCP in community-based long-term care—specifically the MI Choice Waiver—and to establish the State's expectations for provider agencies' policies and practices.

Grant staff also developed an educational module to define the activities that local organizations can use to implement PCP from their boards, through the staff and management to the consumers and community. The guideline was written using an inclusive process with consumers, advocates, providers, and policy staff and is currently being field tested and reviewed by a broader audience of stakeholders.

Outreach and Education

Grant staff provided outreach, education, and training to service providers, advocates, consumers, and family members concerning methods, resources, and products that can promote the use of IP principles. Topics covered include self-determination for individuals with mental illness, fiscal intermediary services, waiver-covered services, and individual backup plans.

Grant staff also developed materials for persons with serious mental illness and for local agency staff about PCP and aspects of self-determination, such as how to use the agency with choice service model. Grant staff developed a bimonthly Self-Determination Implementation Leadership Seminar as a forum for sharing information and strategies as well as clarifying technical requirements. In these sessions, communities that have quickly implemented self-determination arrangements are sharing policy documents with communities that have been slower to implement.

Grant staff partnered with a grassroots advocacy group called Michigan Partners for Freedom (MPF) that provides information about independent living, self-determination, and peer mentoring to consumers and families in several geographic areas of the State. During the grant period, MPF provided leadership training to 624 individuals with disabilities and 195 family members to develop empowerment, advocacy skills, and awareness of state and local issues. This training also explains the basics of developing and participating in self-determination arrangements. MPF focuses on expanding knowledge about self-determination for persons with developmental disabilities and their advocates, but its efforts seek to involve anyone who wants to learn more about self-determination.

Grant staff also worked with the Paraprofessional Healthcare Institute to create and conduct a train-the-trainer program for a curriculum on "Employing, Supporting and Retaining Your Personal Assistant." This initiative developed seven teams of consumer and staff trainers, created a curriculum designed for both consumers and staff, and developed materials for use with participants in self-determination arrangements who wish to learn how to hire and manage their own staff.

Statewide annual self-determination conferences have been held each year of the grant project, with typical attendance at more than 500 people, half of whom are consumers and family members. These conferences have served to showcase progress and serve as learning laboratories for others interested in self-determination.

Challenges

Implementing self-determination policy and practice in the mental health services delivery system has been a major challenge. Resistance and misunderstanding among local service delivery agencies have delayed the development of a series of documents to define and describe recommended practices for self-determination implementation. Local agencies' adoption of these practices has varied from one part of the State to another, depending partly on local leadership, and some areas have not adopted them at all.

The State has found that the nature of services and supports for persons with mental illness has posed a challenge to the development of individual budgets. Many supportive services for persons with mental illness are combined and billed at a combined rate (e.g., Assertive Community Treatment), making it difficult to determine the amount that would be available for one individual budget. This issue arises most often when states offer rehabilitative services in their state plans or in an HCBS waiver program, because they have used reimbursement methodologies that combine payment for multiple rehabilitative services performed by multiple practitioners within a single combined rate. The challenge is to develop a method to cost-out the amount of funds available to an individual who wishes to self-direct his or her mental health services in an individual budget.

Another challenge is that the "unbundled" individual cost for certain services, such as group therapy, can be very low. A potential approach to addressing this problem is the development of consumer cooperatives that pool individual funds for several consumers who are working together to directly manage their services. Michigan developed such a cooperative model with an FY 2001 Real Choice Systems Change grant, and one cooperative is currently operating.

Outcomes and Enduring Systems Improvements

The IP grant activities have resulted in the following enduring improvements: (1) Grant staff helped to develop new expanded service definitions in the Managed Care Specialty Supports waiver program—a combined 1915(b) and (c) waiver—that includes peer support services. Participants may select a peer with experience to assist them in developing skills for recruiting, hiring, and managing personal care assistants; with developing and using an individual budget; and with using an independent support broker. (2) The approval for a self-determined services option within the MI Choice waiver was formally granted for four pilot sites in October 2006. Participants may now directly hire personal assistants and use fiscal intermediary services. The State intends to expand the option statewide pending CMS approval of the renewal application for the MI Choice waiver, effective October 1, 2007. (3) The Department of Community Health has instituted a new contractual requirement for Prepaid Inpatient Health Plans and Community Mental Health Service Programs to implement the Self-Determination Policy and Practice Guideline.

The IP grant effort has been part of a systemic approach to transform service and supports delivery in Michigan's long-term care system to support CMS's New Freedom Initiative objectives. Independence Plus is one of several grant projects that have overlapped, thus providing a synergistic effect. For example, the State was awarded an RWJF Cash and Counseling (C&C) grant in 2004, and the PCP training and products developed under the IP grant for the MI Choice waiver are being used in the C&C project. The IP grant is also being used to encourage the development of employment options as part of PCP, and this work is informed by the CMS Medicaid Infrastructure grant project intended to reduce barriers to employment for persons with disabilities. The IP grant's PCP and self-determination materials and approaches will be used in the State's four newly established single point of entry demonstration projects established in part with an Aging and Disabilities Resource Center grant. Michigan's Systems Transformation grant, awarded in September 2006, will build on the work conducted under the IP grant and the C&C grant with the MI Choice waiver program to develop self-determination options by supporting training and dissemination activities aimed toward a statewide implementation of self-determination in the long-term care system over the next several years.

Developing and using strong consumer participation within a task force of stakeholders was a strategy common to all of the State's Systems Change grants. One of the outcomes from this multi-grant effort has been the ongoing participation of consumers, advocates, and agency staff in the development and implementation of policies and contractual mandates that support self-determined services arrangements. Central to these efforts is the expectation that the PCP process will identify consumer preferences, help the consumer set personally important goals, and be the basis for the plan of service.

MISSOURI

Prior to receipt of the Independence Plus (IP) grant, Missouri's Department of Mental Health (DMH) offered the option to self-direct personal assistant services in three DMH waiver programs serving persons with mental retardation and other developmental disabilities: the Community Support waiver for children and adults; the Comprehensive waiver for children and adults; and the Sara Lopez waiver, a model waiver serving up to 200 children from birth through age 18. Participants and families may elect to serve as the employer of record for personal assistance workers, and a fiscal intermediary provides payroll services for participant-employed workers.

Self-direction has also been available to persons over age 17 who have a physical disability under the Medicaid state plan service—Consumer-Directed Personal Care—and through the Independent Living waiver, administered by the Department of Health and Senior Services, which serves adults aged 18 through 59 with disabilities.

Independence Plus Grant Initiative

The IP grant was awarded to the DMH Division of Mental Retardation and Developmental Disabilities (DMRDD) in partnership with the Missouri Planning Council and the Institute for Human Development, Missouri's University Center for Excellence. The grant's primary goal was to enable the DMRDD to plan, develop, and implement a self-direction system to enhance choice and control of services and supports for adults with mental retardation and other developmental disabilities, physical disabilities, and mental illness.

Grant staff implemented a pilot program to test the use of individual budgeting, new financial management services models, and support broker services in the Comprehensive and Community Support waivers for persons with mental retardation and other developmental disabilities. They recruited 33 waiver participants—aged 8 to 60—from rural and urban areas to participate in the pilot and trained 18 person-centered planning (PCP) facilitators and 28 support brokers. Grant staff also developed workbooks to orient participants to the pilot program and assist them with service planning.

The pilot program, which was completed in September 2006, included the following features:

- A choice of support brokers and PCP facilitators and the option to hire neither if participants felt that their DMRDD service coordinator (trained in PCP and familiar with fiscal management services) provided sufficient assistance. Those who were hired could be "independent" (e.g., a neighbor or relative), work for an agency, or work for the DMRDD as service coordinators who do not make decisions about program eligibility.

PCP facilitators and support brokers are considered waiver services, and their cost is paid for out of the individualized budget.

- An individual budget equal to the total dollar value of the services and supports specified in the Individual Support Plan under a participant's control and direction.
- The development of an individual backup plan, which addresses different scenarios and plans for dealing with them.
- A system backup process to ensure staff coverage for participants, which includes the 24-hour availability of staff who can be called to address backup issues and an employee call-in system in which workers clock in and out by telephone. Individuals have emergency backup plans in place that designate who is responsible to assign temporary staff in the event that an employee fails to report to work.
- The continuing support of a DMRDD service coordinator responsible for monitoring health and safety, completing waiver documentation requirements, and advocating for the participant when needed.
- A choice of financial management services to handle payroll tax and other employer-related responsibilities: the fiscal employer agent or the agency with choice model.

The pilot was funded with the participants' current budget/allocation for services through the Comprehensive or Community Support waiver program, whereas grant funds paid for independent planning facilitators, independent support brokers, and fiscal management services that are outside the current DMRDD waiver contract.

Although training in PCP is provided at all levels—to direct support staff, case managers, administrators, and independent plan facilitators—the State believes that PCP and support brokering require different skill sets. PCP facilitators (called Community Specialists under the waiver programs) perform services that include professional observation and assessment, individualized program design and implementation, training of consumers and family members, consultation with caregivers and other agencies, and monitoring and evaluation of service outcomes. Such services require a higher skill set than those provided by support brokers, who primarily assist participants in arranging for, directing, and managing services. Thus, the Community Support waiver program requires PCP facilitators to have a 4-year degree and be credentialed as a qualified mental retardation professional, which is not required for support brokers.

Given the differences in skill sets, the State established two separate positions—PCP facilitator and support broker—with different training requirements. A PCP facilitator is chosen by and works under the direction of a participant or (if under age 18) a parent/guardian to facilitate the planning process. The facilitator's role includes the following:

- making sure the planning and work go more smoothly;
- ensuring that the values and assumptions of person-centered work are used in the planning process;
- facilitating the group learning process, keeping the planners focused on the individual and his or her vision, and assisting planners in translating ideas into action;
- ensuring use of good communication and interpersonal skills in the planning process;
- encouraging everyone to participate, keeping the work moving, and helping planners to summarize and clarify their ideas; and using group graphics to capture discussion, direction, and action steps; and
- ensuring that the planning process occurs in an efficient, effective, and timely manner; and that summarized planning outcomes are disseminated to all group members.

A support broker is someone who is chosen by and works under the direction of the participant or (if under age 18) his or her parent/guardian, or a designated personal advocate. The broker serves as the participant's personal agent to secure supports that meet the needs identified by the participant in the support plan and applies the principles of self-determination. The support broker's responsibilities can include, but are not limited to, the following:

- assisting the participant/family in evaluating various options and available resources, as well as in understanding the pros and cons of each option/resource;
- navigating community resources;
- developing community connections;
- recruiting, hiring, managing, and negotiating rates and contracts with the chosen providers of personal assistance services, when desired by the participant or family;
- establishing work schedules for supports based upon the person-centered plan, when desired by the participant or family;
- training and supervising personal assistants, when desired by the participant or family;
- discharging providers of support when necessary;
- developing and implementing a backup/emergency plan to meet the participant's needs as designed in their support plan; and
- assisting with managing the individualized budget when requested/needed.

Individuals may complete both PCP and support broker training and fulfill both roles for an individual.

Outreach and Enrollment

Grant staff produced a pilot project recruitment brochure targeted to current waiver participants and their families, and PCP facilitator and support broker recruitment announcements. They also created a project website with information and resources that are updated regularly and include a description of the pilot project, a definition of self-determination, a listing and discussion of the supports available, and educational materials such as workbooks designed to orient participants to the self-determination philosophy and the individual budgeting process. The website is at www.ihd.umkc.edu/independenceplus/.

Enrollment in the pilot program was low for several reasons. First, some individuals need around-the-clock care and these families need more than four employees to provide this care. In Missouri, employers with more than four employees are required to provide workers' compensation insurance, and the State has not yet been able to find reasonably priced insurance, which would have to be paid from the individual budget. Too high a cost could result in a substantial reduction in the funds available for services, which is a disincentive to enroll. Some families obtain their own workers' compensation insurance through their homeowners insurance. Second, many participants are already using the hire/dismiss option and some are satisfied with the services they are receiving. For them, transitioning to a new system that is more complex and entails the assumption of new responsibilities can be a disincentive for enrollment. Third, some waiver participants receive services through multiple programs, and the complexity of managing a budget for some, though not all, of the service package could constitute another disincentive.

Pilot Challenges

Recruiting support brokers was difficult in sparsely populated areas given what a large state Missouri is—it can take 15 hours to drive from one part to another. If only one person in a remote area was interested in participating, it was not possible to include that person in the pilot. In this instance, they were referred to the consumer-direction option in the waiver program (if they were not already enrolled). To address this challenge in the Comprehensive and Community Support waivers, the Missouri Planning Council for Developmental Disabilities will be funding a project to recruit and train support brokers throughout the State in fall 2007.

One of the grant's goals was to combine funding from multiple programs administered by different agencies in the individual budgets for pilot participants eligible for more than one state or Medicaid program. Grant staff explored the possibility of combining funds but were unable to do so during the pilot because of numerous staffing changes at several agencies. The State is continuing interagency discussions about combining multiple funding streams into one individual budget. The State received two Systems Transformation grants—one from the Substance Abuse and Mental Health Services Administration (SAMHSA) and one

from CMS—and a Money Follows the Person demonstration grant. The work on these grants will include interagency discussions to increase flexible funding of services.

Outcomes and Enduring Systems Improvements

As part of the renewal application for the Comprehensive and Community Support waivers, the State added an individual budgeting option, independent PCP facilitators, financial management services, support broker services, and an individual backup and incident management system. The two waivers were renewed July 1, 2006, and about 15 families currently are using support brokers. Services that participants may self-direct are limited to personal assistant, in-home respite, community specialist, and support broker.

The State is planning to amend the Sara Lopez waiver to add the same components and is committed to improving self-direction services in all programs by addressing operational issues; for example, by providing a choice of fiscal intermediaries, finding affordable workers' compensation insurance, and expanding individuals' budgets to include goods as well as services.

When the pilot ended, the State decided to continue meeting with the pilot's Advisory Group—comprising consumers and family members, service providers, advocacy organizations, support brokers, and others—to receive ongoing input on self-direction issues that the State is working on, such as workers' compensation insurance. The Missouri Planning Council has been covering some of the expenses for these meetings.

MONTANA

Prior to receiving the Independence Plus (IP) grant, Montana offered self-directed personal care services under the Medicaid state plan, using an agency with choice model. Participants can hire and dismiss workers but do not have control over an individual budget, whereas the agency sets the pay rate and covers workers' compensation. Self-direction was also available through the Elderly and Physically Disabled waiver program for extended personal assistant services, including socialization, and homemaker and respite services. The Department of Public Health and Human Services applied for an IP grant in response to the state legislature's request that the Department examine self-direction options beyond those currently offered, including ones that give consumers responsibility for planning, budgeting, and spending—which the State considers to constitute "advanced consumer direction."

The Department initially planned to submit a research and demonstration (R&D) waiver application to give state plan participants enhanced self-direction options. However, with limited staff resources to administer an R&D waiver program, the State decided to apply for a new HCBS waiver—the Big Sky Bonanza (BSB) Independence Plus waiver—and to pilot it in six counties before expanding it statewide. Current Elderly and Physically Disabled waiver program participants can choose to enroll in the new waiver if they want to use the expanded self-direction option. However, in response to the success of the pilot and the changes in CMS policy, the State is considering amending its statewide HCBS Elderly and Physically Disabled waiver program to include the options in the BSB program.

Independence Plus Grant Initiative

Grant staff obtained ongoing input on the design of the new HCBS-IP waiver program from consumers—particularly current waiver program participants and their families—tribes, community service providers, advocates, personal assistants, case managers, and Independent Living Centers. To gather input and feedback for the design of the BSB waiver, grant staff conducted focus groups with consumers served through the existing self-direction options in the state plan and the Elderly and Physically Disabled waiver program. A Native American Coordinator at the Montana Center on Disabilities, Montana State University, led outreach to Indian Nations in order to ensure cultural sensitivity in all phases of program development and implementation.

Person-Centered Planning

Montana's grant stakeholder group reviewed several states' person-centered planning (PCP) models before selecting Florida's model as a guide, which was then tailored to fit the State's program. The new IP waiver's plan of care document includes a spending plan for services and supports. Many consumers considered the plan of care to be too complicated and

repetitive. Others found the 8-hour training, which incorporated PCP concepts, to be burdensome because they knew what services they needed and wanted to finalize their budgets without having to reiterate long-term life goals. As a result of consumer feedback, the State is simplifying the training and the assessment and enrollment process.

Grant staff noted, in retrospect, that a cumbersome and complicated planning process limited support brokers' effectiveness in working with consumers and hindered enrollment. They recommended that other states not "person-center the process to death like we did" and that they test the planning process with just a few consumers and providers with the goal of simplifying it before implementation.

To further support PCP principles, the state contractor that makes level-of-care criteria determinations developed a report, which is distributed to consumers and support brokers on completion of their assessment. This report provides critical information on service authorization and health and safety, identifying specific health and safety issues. The report is designed to assist consumers and support brokers in the PCP process and in the completion of the Support Service and Spending Plan within the authorized individual budget.

Individual Budgets

Individuals in Montana who are currently receiving state plan personal assistance services (PAS) but choose, if eligible, to be in the new HCBS-IP waiver program, receive a comparable resource allocation for services they were receiving through the state plan in their waiver individual budget to use for a variety of self-directed services. The state contractor conducts a needs assessment and makes the level-of-care determinations, and the State uses the PAS cost information and historical waiver service costs to determine individual budget amounts. The individual budget gives waiver participants budget and employer authority over a range of goods and services, including Native American healing services, which were added after obtaining feedback from the Tribes.

Financial Management Services

In Montana's HCBS-IP waiver program, participants have the option to select the fiscal employer agent model or the agency with choice model. Currently, all participants in the BSB program have selected the agency with choice model, which the State calls the "co-employment" model. The participant is responsible for hiring, managing, and dismissing workers, setting payment rates (within specified parameters), and scheduling services and supports. The financial management services (FMS) agency is the employer of record and the Medicaid provider for self-directed goods and services. In the latter capacity, the agency can issue payments at the direction of the consumer. Montana's training for financial

managers included a readiness review upon completion to ensure that they are capable of performing all fiscal and budget support functions for the IP waiver.

Support Broker Services

Montana's work group designing the support broker, individual budgeting, and FMS components considered the traditional case management model using a nurse and social work team to be inappropriate for self-directed services and wanted to use the independent living and PCP philosophy for support broker services. In response, the State expanded the provider base for support brokers beyond traditional case managers to include local agencies committed to self-direction principles and the PCP philosophy. The State certified nine community agencies as support brokers and FMS providers, a diverse group that included Independent Living Centers, waiver case management teams, PAS agencies, and Area Agencies on Aging. Tribal agencies may also become support brokers and FMS providers. The State designed the support broker and FMS components in collaboration with two tribes and modified the degree requirements to enable tribes to become providers.

Quality Assurance and Quality Improvement Systems

Grant staff developed an individual risk assessment tool to guide participants through a process of identifying and developing plans to prevent and reduce risk, and to address problems when they arise. Consumers and support brokers are trained to use the tool, which is unique to the waiver, as part of the PCP process; the State is considering using it in the traditional waiver and the state plan. The State also developed a quality management process to monitor and manage participant health and well-being in the new IP waiver. The process uses a three-tiered method to ensure quality: Tier I is the individual and provider level, Tier II is the regional level, and Tier III is the state/division level.

Outreach and Education

Grant staff believed that efforts to gather stakeholder feedback prior to the design phase were beneficial. Much of the feedback came from consumers who were active advocates in their communities. Grant staff noted that future planning efforts should also try to obtain input from other consumers.

To recruit participants for the new IP waiver, the Department sent a letter and informational brochure to all current participants in the Elderly and Disabled waiver program, and case managers discussed the new waiver with clients undergoing annual reviews.

The Department contracted with Summit Independent Living Center to develop and provide the initial orientation and training for consumers and providers. In the future, regional state staff will be responsible for this activity. The Center developed an orientation presentation and guide to educate consumers, providers, and the public about consumers' roles and

responsibilities in the IP waiver and conducted two orientation sessions in two pilot areas attended by both consumers and providers. The Center also developed consumer, support broker, and financial manager training curricula and manuals and conducted training sessions in two pilot areas.

Challenges

The complexity of the new waiver made it challenging to assure some stakeholders that the new features were a "value added" and did not reduce services and supports. For example, some stakeholders did not understand why state plan personal assistance resources were included in the waiver program's individual budget and thought the State was taking away services and supports. Also, the report outlining the individual budget determination was perceived as too complex because it included the budget calculation formula, leading to concerns that consumers would have fewer resources under the new waiver program.

Grant staff thought that FMS agents serving state plan participants using the self-direction option would easily be able to provide services under the new waiver, but this was not the case. More hands-on training about individual budgeting and the PCP process was required. Steep increases in workers' compensation rates have also posed a financial challenge to providers. Nevertheless, several providers became certified support brokers and financial managers.

In spite of outreach efforts to include Indian Nations, Native Americans did not participate in the pilot, largely because of issues related to tribal relations with the federal government (generally, tribes wanted the Medicaid funding to come to the tribes directly from the federal government).

Outcomes and Enduring Systems Improvements

The Senior Long Term Care Division of the Montana Department of Public Health and Human Services submitted an Independence Plus 1915(c) waiver application, which CMS approved in January 2006. The new waiver program incorporates the self-direction features of an individual budget, financial management services, support broker services, and person-centered planning. In July 2006, the waiver program was open to enrollment in the six pilot counties and the first two clients enrolled in September 2006. Currently, nine individuals are enrolled, including several children.

The waiver includes a provision stating that it must be amended by CMS to move beyond the pilot stage, supporting the State's intentions to obtain feedback from pilot participants and make changes as needed. CMS granted a 1-year grant extension to enable grant staff to streamline the enrollment process and develop a quality assurance database for use in all HCBS waivers. As noted earlier, based on the pilot's success and changes in CMS IP policy,

the State is considering amending its statewide HCBS Elderly and Physically Disabled waiver program to include the options in the BSB program. Doing so could reduce the administrative costs associated with two separate waivers.

Enrollment has been slow, with stronger than expected interest from parents of children with disabilities than from elderly persons. Because satisfaction with the current waiver program is high, the benefit of the individual budget and other self-direction options may not be immediately apparent. Grant staff noted that enrollment for the self-direction option for state plan personal care services also was slow when it began in 1995. As consumers and providers gain experience with the IP waiver, it is expected that they will share it with other consumers and providers, which can increase interest and enrollment.

OHIO

Ohio received a self-determination grant from the Robert Wood Johnson Foundation in 1997, which it used to develop an individual budgeting option for persons with mental retardation and other developmental disabilities. The grant project served 222 individuals in four counties. Subsequently, the Ohio Department of Mental Retardation and Developmental Disabilities (ODMRDD) allocated $1.6 million in state revenue over 2 years for a statewide training initiative—Self Determination in a Medicaid Environment—targeted to county board employees, service providers, and people with disabilities and their families.

Although the State's MR/DD waivers do not have a self-direction option, some counties fund self-direction programs using local funding. Ohio's Department of Aging currently administers the State's only consumer-direction waiver—*Choices*—but the Ohio Department of Jobs and Family Services is considering adding a self-direction option to its Home Care waiver, which serves persons with physical disabilities.

Independence Plus Grant Initiative

The Independence Plus (IP) grant was awarded to the ODMRDD. Its primary purpose was to expand self-direction options for persons with mental retardation and other developmental disabilities by developing an HCBS-IP waiver to serve individuals in specific counties statewide. The State has been granted a 6-month no-cost-extension and will conclude grant activities on March 29, 2008.

Grant staff have established three groups to address three levels of policy work: (1) a work team in each of the participating counties; (2) a statewide collaborative group representing all the participating counties and other stakeholders; and (3) an IP Advisory Committee, which includes persons with the expertise or authority to help eliminate barriers and establish the infrastructure needed to support implementation of the HCBS-IP waiver. Members of the three groups helped to design the new waiver program.

In addition to operating the Medicaid program, Ohio counties contribute local funds toward the State's Medicaid match. The ODMRDD therefore sees the county MR/DD boards as important stakeholders and wanted the counties to have input in the design of the new HCBS-IP waiver program and to determine whether they want to participate in the program. Ohio has 88 counties, all of which were invited to participate in the new IP waiver program on a voluntary basis. Currently, 15 counties have agreed to participate, and reaching agreement among them on various waiver design issues has been a challenge. Ohio has requested a waiver of statewideness for the first 3 years and will consider implementing the IP waiver program statewide in the following years.

In preparation for implementing the support broker service for participants, grant staff conducted statewide trainings for state and county staff on the support broker's role and responsibilities. They also gave the 15 participating counties a set of self-assessment questions to determine their technical assistance needs. The results of these self-assessments also provided input for the design of the new program.

Grant staff and stakeholder groups are working on several provisions in the new waiver program, including those related to consumer options to be the employer of record or to enter into a co-employer relationship with a financial management services entity. Consumers will create their own individual service plan (ISP) based on what they want and need; the dollar amount of the individual budget will be based on the services identified in their plan. Grant staff are also working on quality assurance provisions, which will include monitoring of ISP implementation by participants and their support brokers to ensure that desired outcomes are being achieved.

Grant staff and the ODMRDD have also developed a transition policy that will enable IP waiver participants to transfer to the Department's Independent Options (IO) waiver if they cannot or choose not to continue in the HCBS-IP waiver. The State intends to earmark IO waiver slots for this purpose.

When the waiver's provisions are finalized and approved by CMS, grant staff will develop training and technical assistance materials and informational brochures to educate individuals with mental retardation and other developmental disabilities, families, and all other stakeholders in the participating counties about the new service options under the HCBS-IP waiver and the enrollment process. Preliminary discussions have taken place regarding the types of training and technical assistance materials that will be needed and how they will be distributed.

Challenges

Reaching consensus in the MR/DD field has taken much time and effort. The State wanted the IP initiative to be a "grassroots/from the ground up" initiative, and so numerous stakeholders with very diverse views were involved. To assist in reaching consensus, the ODMRDD contracted with an outside entity—the Center for Self-Determination—for the first 2 years of the grant to facilitate the meetings and to bring a national perspective on self-determination to the stakeholder group. Grant staff recommend this as a highly effective approach.

Another challenge is related to the State's use of 88 county MR/DD boards to oversee the State's two waiver programs that are administered by the ODMRDD. Because the programs are operated at the local level, they do not have a single standardized assessment tool to develop an individual's service plan, which CMS prefers in order to ensure comparability in

the determination of individual budgets. Consequently, the State has had extensive discussions with CMS to provide assurances that using the same set of core questions for all enrollees in the IP waiver can ensure comparability in the absence of a standardized tool.

Outcomes and Enduring Systems Improvements

The new HCBS-IP waiver application was submitted to CMS in draft form, and CMS provided written feedback that is being incorporated into the final application. The initiative received a setback when some stakeholders objected to the statutory language needed to implement an HCBS-IP waiver in Ohio. As a result of their lobbying, the authorization was removed from the Budget Bill in 2006. Grant staff are now working with a small stakeholder group to reach consensus on the legislative language. They hope to submit the application to CMS sometime in the next few months. Once approved, the State plans to implement the program in 15 counties.